University of Alberta

A NARRATIVE INQUIRY INTO MOTHERS' EXPERIENCES OF SECURING INCLUSIVE EDUCATION

By

Heather Raymond ©

A Thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment
of the requirements for the degree of Doctor of Philosophy

Department of Elementary Education

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ABSTRACT

The research, a narrative inquiry, explored two mothers' (one each from Canada and Australia) experiences of securing inclusive education for their sons with developmental disabilities. Field texts were composed from extensive conversations between researcher and two participants. The participants were invited to tell and retell their parent experiences of securing and maintaining an inclusive education for their sons.

Narrative accounts of the mothers' experiences were written. The mothers' narratives were re-presented in poetic transcriptions in order to both give our work an aesthetic sense and to highlight the emotional and moral components of the experience. The narratives of experiences also foregrounded the dominant social narrative on school landscapes which shaped and resisted these mothers' personal practical knowledge.

Four themes emerged in the analysis of the mothers' narratives. The first theme, "What Counts as Knowledge? Whose Knowledge Counts?," explored the mothers' understandings of how their knowledge was constructed from their personal experiences, as mothers in relation to their sons, and how their knowledge was received by those who live on the professional knowledge landscape of schools. The second theme, "School Transitions," explored the mothers' narratives of their sons' transitions as different from the routine transitions most children encounter in school. The third theme, "The Gazes of Others," explored the mothers' narratives of others' gazes and how these gazes shaped plotlines for their sons inconsistent with the plotlines they wished to have constructed for them. The fourth theme, "Advocacy," explored the mothers' narratives that led to their emerging roles as advocates as they worked to author stories of inclusion. The final chapter is a reflective turn on the research experience from a principal's position on a school landscape.

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CHAPTER I

INTRODUCTION

I begin with my personal narrative so as to acknowledge how my own experience is located within my research work (Clandinin & Connelly, 1994; Edmonds & Ribbens, 1998; Mauthner & Doucet, 1998). "Composing our own narratives of experience is central to narrative inquiry" (Clandinin & Connelly, 2000, p. 70). My narrative account is of a time when I was a member of a group supporting a family in their effort to secure inclusive education for their son with developmental disabilities. While the narrative reads as a story of others, it is my story of learning to advocate as a participant within a "grassroots" movement (Adamson, Briskin & McPhail, 1988). In composing this narrative, I reflect upon how I experienced advocating, organizing and changing through the experience. In this reflection, I try to make meaning of this experience to discover how it has shaped my understanding of advocacy and of myself as an advocate for inclusive education.

Through the development of my own narrative I am accounting for myself. The construction of my narrative has helped me to locate myself in my research concern of seeking to gain an understanding of, and to make meaning of, mothers' narrative accounts in securing inclusive education for their children with developmental disabilities. My narrative is important because my research wonder has not come out of a vacuum, but has emerged from my own experiences, as well as from the minimal presence of the "topic" in the research literature.

RECONSTRUCTING THE STORY

This narrative was reconstructed through document resources that included notes, minutes, letters, and scraps of paper from meetings and correspondence between a parent and a school board saved and archived in my home. In addition to reading through these textual representations, I relied on my personal memory of my perceptions and understandings, and on conversations with my husband, who was also a member of the support group. These memories were important because textual representations leave out some of what happened: how the meetings felt, the unspoken meanings shared through gestures, the relationships that formed between the support group participants. It is through the telling and retelling of this lived story that my "...personal memory in which the emotional meaning of events is recognized..." (Hoffman, 1994, p. 3) and helped to bring this internal journey to the narrative.

This narrative is the account of my experience. In other words, it is my version of events and my interpretation of them. While I lived this story of "advocate" (McAdam, McCarthy & Zald, 1988), others were storying me (Clandinin & Connelly, 2000). This is not a story about their storying of me or the stories that they lived. It is the telling of my story of learning to be an advocate. We can only wonder what the stories were of those whose lives interconnected to this narrative. In Silko's (1996) words, every "... story (is) composed of innumerable bundles of other stories" (p. 31). There are multiple stories but they will not be heard here for I only have my story composed years after participation. At the time of this lived experience, the intention of my participation was not for research purposes.

Intertwined within the narrative are my reflective interpretations on what I learned about advocacy. In the moment, I did not have this understanding. Time allowed me to reflect upon and understand this learning. Within the narrative I draw connections to social movement theory and the organized social actions connected to the women's movement and other groups working for social change. These groups' social actions represent the kinds of options available for social change efforts (Minkoff, 1995). The literature on social movement theory and the women's movement provides a useful frame to reflect upon the ways grassroots groups' influence and achieve change. This literature provides a backdrop within the reflective and interpretive process of writing the narrative.

In formatting my story I have used four different fonts to create a sense of the layers within the narrative: regular "Times New Roman" font describes what I interpret as having happened; *italic "Arial Narrow" font shows what was written between the Board and parent*; regular "Arial narrow" font is used for words of other authors; and *italics "Times New Roman" text are my reflective thoughts.*

NARRATIVE BEGINNINGS[1]

> I have come to believe over and over again that what is most important to me must be spoken, made verbal and shared, even at the risk of having it bruised or misunderstood. That the speaking benefits me, beyond any other effect. ...what I most regretted were my silences.... We can learn to work and speak when we are afraid in the same way we have learned to work and speak when we are tired. For we have been socialized to respect fear more than our own needs for language and definition, and while we wait in silence for the luxury of fearlessness, the weight of that silence will choke us. (Lorde, 1980, pp. 19, 23)

---

[1] Names used in Narrative Beginnings are pseudonyms.

Being – At Risk?

As I embarked on the writing of this narrative I experienced anxiety and an intense feeling of apprehension and fear. The sense was similar to when I first participated in a parent support group to secure inclusive education for children with developmental disabilities. I was anxious about being part of the group because inclusive education was controversial and very political. To be in partnership with parents, talking about the idea of inclusive education, felt as though I was challenging my loyalty (Bloch, 1966). I was a teacher, employee of a board, member of the ATA, colleague, and an aspiring administrator. Although there were districts in Alberta (e.g., Yellowhead School Division) that had allowed children to be included in their neighbourhood school, the act of standing by parents did not seem in keeping with the bureaucratic plotline of teacher as professional. I was stepping out of my role as employee and entering another. I was writing a new script and there was the possibility of a new plotline. I was becoming an advocate, a part of a social movement interested in securing inclusion for all children. To write a new script with a different plotline would be risky within the existing landscape of schools. This landscape is one where professionals were loyal to the script of schools that had borders placing restrictions on children in their movement between 'regular' and 'special' education. At the time of writing this personal narrative I once again wondered what it meant to be loyal. Telling this story would be a risk, wouldn't it?

I always felt a hushed silence among colleagues in response to my advocacy activities for inclusive education for children with developmental disabilities. Through my years as a teacher and assistant principal, I would talk fleetingly about my membership with parent advocacy groups, being asked to be a speaker and attending *national and international events on inclusion. In my teacher world I would not begin conversations about inclusive education but would wait for others to start the conversation. And still then I would walk cautiously. Outside of school I lived a secret life – activist. Telling this story would be a risk, wouldn't it?*

Why Take the Risk of Telling

How can I remain silent when I have had to deal with the anger generated in me by the injustices I witnessed like the time:

My heart ached as I listened to a friend say over a board room table, "That is my child they are talking about as if he is a monster in the 'Trying to Teach' (Alberta Teachers Association, 1993) document;" or

When a teacher called to say to me, "Do you really think she should be in our class, after all she is mentally retarded?" She was talking about Barb's child, Susan. Susan who was a cherished member of my Grade 1/2 class the previous school year (Raymond, 1995). The little girl who taught me and the other children what caring is all about; or

The time I felt ashamed as an educator when I sat at Mary's table listening to her say an educator told her that her child was too intelligent to be included because he would understand he was different; or

The day I had to fight back the tears when two mothers from another school district came and visited my class to see how Susan was included. Their desire to have their children included in a regular classroom was being denied.

Listening to the parents' desires for their children to be included in their neighbourhood school underscores for me the ways in which our experiences of the *world connect us rather than divide us. They too are dealing with educational institutions: the same ones that I find make me feel ever so little and suggest that I should censor what is in my heart; the same ones where I may not say I do not admire special education and feel I must curb my emotional passion for social justice; the same ones where I wish I could rethink my role as a teacher of children with developmental disabilities in small and large ways, painfully and fruitfully in a hope to help children cross the border from special education to regular education. I have learned how to belong within two contexts at the same time, remaining silent within the landscape of schools while advocating for parents in their quest for inclusive education off the school landscape.*

> What I am more concerned with is my sense of loss of power and agency in my life, through this well-rehearsed subversion and management of my feeling voice. (Ribbens, 1998, p. 33)

This past decade has been filled with having to endure the scorn of others. I am tired of defending my desire to work in an inclusive school. My interest to explore inclusion as a reality is not intended to rebuke others. I do not believe teachers who do not support inclusion are less gentle, less empathetic or less responsive than I am. I too have difficulty finding a way to think about what a more cooperative, just and equitable social order might be. However, community for me is, and must be, inclusive for exclusivity in my view is harmful to community.

My teaching and personal life experiences led me to view community as a metaphor of a kaleidoscope. The kaleidoscope requires all the bits and pieces. Remove some, the resulting pattern is less complex, less rich; add others, the resulting pattern is *vibrant and diverse. Together, the kaleidoscope pieces create uniquely beautiful patterns, patterns that cannot be created by one piece or any group of pieces alone. The kaleidoscope patterns are continually changing. Alone we are bits and pieces of this and that. When put together, we become beautiful patterns of what I call community. The inclusion of all people ensures environments that promote individual value and respect. By including all children, as members of a regular class, communities become complete and rich. Exclusion would create a void.*

Kaleidoscope of Children

The essences are each a separate glass,

Through which the sun of beings light is passed,

Each tinted fragment sparkles in the sun,

A thousand colours, but the light of one. (Author Unknown)

What is Advocacy?

Merriam-Webster's (1999) on-line dictionary describes advocacy as the act or process of advocating or supporting a cause or proposal. Webster's New Collegiate Dictionary (1980) defines an advocate as **1:** one that pleads the cause of another; *specifically*: one that pleads the cause of another before a tribunal or judicial court **2:** one that defends or maintains a cause or proposal.

When this story of advocating with and for a family was lived, I had no understanding of what advocacy was and should be. What I brought with me was my personal belief in inclusive education. In time I was to come to learn that advocacy means to seek a solution to a particular issue or need, both with and for people with disabilities in order to enhance their rights and opportunities. I was to be "...challenged to hold firm to a belief in the miracle of commitments that are unconditional and sustained..." (Smith, 1997, p. 139) through relationships with parents who keep me going by their hopefulness.

The Story Must Be Told

> ... advocacy on behalf of the disadvantaged is not unprofessional... and the use of power and influence to achieve worthwhile objectives is not a waste of time. On the contrary, a professional commitment to social change in today's world requires that myths and stereotypes such as these to be buried once and for all. (Dluhy, 1981, p. 7)

Audre Lorde's (1980) words speak to me, "silence will choke us" (p. 23). *I have come to realize that this story needs to be told. I needed to tell what I knew although I worry what the telling may unfold.*

How I Got Involved

I did not just wake up one morning and think, "Hey, I want to be part of a parent group interested in inclusive education." It was more like I was driven to it because circumstances made it the logical thing to do. I attended a summer institute on inclusive education at McGill University (Raymond, 1995) that changed my sense of responsibility as a teacher. I had come to understand that advocating for inclusive education would be best accomplished if collaboration between professionals and families took place (Turnbull & Turnbull, 1996). I learned that in Ontario such a collaborative group formed called "Integration Action Association, Ontario." I knew a parent in Edmonton was interested in forming a support group with the focus of inclusion. While attending a conference in Edmonton I met with this parent and, in conversation, said we should form a similar group. My words were put into action by this parent and, before I knew it, I was at a Saturday meeting at her home with 35 other people that she rustled up to attend. This was the beginning of the group called " Integration Action Association for Education – Alberta (IA)."

I had a sense of excitement and apprehension on the day of the meeting. The conception of IA made real the act of advocacy for me. No longer could I just talk. My turmoil and the enthusiasm created by the participants at the conception meeting left me with an odd feeling that day. I knew this was going to be exciting but I was worried about how the story of advocate might mix with story of teacher, employee of a board, member of the ATA, colleague, and an aspiring administrator. "... there was a new ingredient, an emotional undertow that I'd never encountered before, ..."(Edmond, 1999, p. 278). *This emotional struggle is still with me.*

At the time, I certainly did not tell a story of myself as activist. However, the thought that parents' requests for inclusion were being rejected galvanized me in my wish to help parents access inclusive education for their children and to ensure that it was quality education. I had become conscious of the inconsistencies in the limited options parents with children with developmental disabilities were presented and felt the need to join others in changing this (McAdam, McCarthy & Zald, 1988). I cared enough about the issue of inclusive education that I was prepared to incur significant costs (professionally and personally) and was willing to act to achieve these goals by being an active member of the group (Oliver & Marwell, 1992).

Learning Together – We Become Knowledgeable

We met every month. The group was made up of parents that had secured inclusion, parents who wanted inclusive education for their children and parents who were still considering it. The meetings were friendly and welcoming. They were quiet one-on-one conversations, lively exchanges, questions asked, questions answered, sometimes tears, more often laughter. They were filled with hope and gave parents a sense of possibility. There was a sense of renewal as parents learned they were not alone in their quest for their dream to have their children attend the same school as their siblings. These meetings gave the first hint of the numbers and range of families who, in isolation, were dreaming of a school experience for their children different than the one offered in segregated settings.

The parents talked about their children's successes and struggles with becoming accepted. We shared our stories, dreams and aspirations. At the time I was a consultant and I shared examples of inclusion I encountered across the province (which were only a few) and my reading of the literature on inclusive education. We were venturing into discussions when not many school boards were discussing the idea of inclusion. The group was important to me. I had a place where I could securely, and without a sense of threat, discuss what I learned at McGill University.

I needed the support group as much and sometimes, I felt, even more than the parents. The sanctity of the group provided me the opportunity to think beyond the limits imposed by the obligation of teacher, employee of a board, member of the ATA, colleague, and an aspiring administrator. I could openly question the models that shaped the delivery of special education in the province and speak of other possibilities. It was a place where a different set of questions was being asked. This was my "public homeplace" (Belenky, Bond & Weinstock, 1997). I, like the parents, experienced *silencing and needed the nurturing of others to develop and struggle to have a voice in the dialogue of education for children with developmental disabilities.*

Participating in a support group to assist parents to advocate for their children to gain an inclusive education made me further question my understanding of present conceptions of education for children with developmental disabilities. To let go of old certainties (segregated education) and to acknowledge another way of seeing education for children with special needs (inclusive education) "requires courage, self-trusting, standing apart, ... because this process often creates temporary confusion the gaining of independent reasoning is both disconcerting and disorienting, both in relation to the established hierarchies and political allegiances and, more painfully, in relation to oneself" (Corbett, 1996, p. 34).

At the time, we would not have described our meetings as consciousness raising (Pierson, Cohen, Bourne & Masters, 1993). But on reflection they were just that. As in the women's movement, "We had boundless energy and sought eagerly to collectivize our experiences, to move away from our isolation and powerlessness" (Adamson et al., 1988, p. 42).

The discussions helped parents to learn that their private experiences with schools rejecting their requests were universal and part of a larger pattern of societal prejudice towards their children (Corbett, 1996; Morris, 1991). The meetings were similar to those in the women's movement. The process of telling about the personal became a distinct form of feminist organization through consciousness raising groups (Adamson et al., 1988; Pierson et al., 1993). Gluck & Patai (1991) give a sense of what was happening within the group: "It is ... true that the telling of the story can be empowering, validating the importance of the speaker's life experience" (p. 2). Acquiring knowledge, sharing information and advocating for inclusive education was a critical part of IA through the telling of personal practical experiences. Through the personal narratives, we (parents and professionals) were raising our consciousness about parents' rights to inclusive education for their children.

Frustration

As I listened to the parents talk about their sense of rejection and struggles with getting educators to understand why and what they wished for their children in an inclusive classroom I often felt frustrated. I could understand the dilemma from my colleagues' point of view because I had been there too. They were struggling with the idea and had few experiences and examples to draw on. I had just awakened to the idea of inclusive education as a choice and was beginning the learning journey of how to effectively include all children.

Although I sympathized with my colleagues about their dilemma of including children with developmental disabilities, at times I got angry about what was happening to these parents and how they were expected to be complacent and to accept without question what was offered to them by school personnel.

Asking for Help

> Making change is by definition the goal of the women's movement. To do so is to challenge social inertia, to empower ourselves, and create a new set of possibilities.
>
> (Adamson et al., 1988, p. 136)

My desire to help parents secure inclusive education was put to a test one day. At every IA meeting the group would tell each other that if one of the parents needed support to get inclusion the group was there to support them. In over a year no one had taken us up on the offer. But this was to change. Close to the end of the September 1988 meeting a parent named Linda put her hand up and said, "I need help."

We looked at each other and *I thought, "What does help mean?" Being one of the few professionals involved in the group I felt a sense of responsibility that mirrored my expectations of myself as teacher. I should know how to do this. I had been reading the literature on inclusive education and attending university courses on how to but part of this was never the nuts and bolts of formally appealing a school board's placement decision. However, more than needing to know how to advocate against a school board I struggled with my personal conflict with being both a teacher and part of such a political activity. To secure inclusion for Linda's son would mean taking a school board to task. Was I up to this? How could I be part of this advocacy effort and safeguard myself? In the weeks, months and the year to follow I was to learn what help meant and would have to face my own personal concerns about being an advocate many times.*

Kitchen Table Advocacy: A Year Long Process

Before the meeting ended members of the group were asked by a show of hands who would be willing to go to Linda's house for a meeting to help her secure inclusive education for her child at his neighbourhood school. I put my hand up (*with a sense of foreboding*) along with a number of other members. A date was scheduled to meet at Linda's house the following week. We consciously moved from the professional boardroom table to the kitchen table. The hardship was on the family and meeting in their home rather than expecting them to travel to the group meeting place might eliminate one stress for them as well as provide Linda the comfort of her home as she shared her story.

One Week Later...

We assembled at Linda's house. Linda was a gracious hostess and was aware that the people gathered at her house had come directly from work. She laid out an array of food (which was to become part of all the meetings at her home over the next year). After we secured a plate of food (*which created, for me, an odd feeling of festivity within an air of tension)* the meeting began by asking Linda to tell what she had done to date to try to get her son included into his neighbourhood school.

She wove a story that resembled a merry-go-round of conversations with different people. She had spoken to her child's teacher, the principals of 19 schools, consultants and senior district staff. They all responded with an unequivocal no to her request to have her son included in a regular Grade 6 class.

> *Dear Mrs. __________,*
>
> *As indicated to you over the telephone, your request for a fully integrated placement for your son, Paul has been denied. (Letter, September 13, 1988)*

Serious Decision

Linda shared her very serious decision to keep Paul home until the dispute between her and the Board was cleared up. After the last IA meeting she became firm in her decision that inclusion was what her son needed and should have. After the IA meeting she contacted a senior staff and indicated that if her son could not go to his neighbourhood school then she would be keeping him at home because she would no longer send him to the district's segregated class in which they had him enrolled. We were all a bit taken aback but respected Linda for her decision and determination. Linda had drawn her line in the sand and we had to choose what side we would be on. It meant we had no time to lose. A child out of school was a serious thing. We needed to work hard to get Paul into the school Linda wanted for him.

A Major Challenge

After Linda updated the group of people assembled we began to brainstorm ways to assist Linda to convince her school district that her son should go to his neighbourhood school. None of us had direct experience with dealing with a resistant school board. We knew, however, that a collective action (McAdam, McCarthy & Zald, 1988) was necessary to change Paul's circumstances. We shared what we knew. The discussion touched on how to recruit more supporters and enlist new allies, influence decision-makers at all levels, and make and keep important contacts. We took inventory and identified our collective skills, talents and abilities and explored our personal contacts (Governor's General Council on Developmental Disabilities, 1989) before we divided the labour.

As we each selected tasks I was cautious about the ones I felt safe to pursue. Contact with the Board in any way was out. This was way too risky. I chose tasks that were neutral in nature and would not be viewed as adversarial to my perceived responsibilities as an educator. I struggled with these ideas at the same time as being committed to helping despite the risks. I felt like I was on a teeter-totter trying to balance being an advocate and being an employee of a school board. I struggled with my sense of identity as I lived on the two landscapes in which I had positioned myself. This haunted me. It was a strain living on both landscapes, weighing every action, weighing every reaction as I negotiated my way through the spaces I lived within both contexts.

The next two weeks were filled with action. Each of us set out to accomplish our assigned tasks. We needed to focus on ways to create interest and support for the goal of getting Paul into his neighbourhood school. Through IA we activated our own commitment but we needed to create opportunities to gain the commitment of others (Ryan, 1992).

The plan included contacting the Alberta Association for Community Living (AACL) and the Canadian Association for Community Living (CACL), advocacy groups for families with children with developmental disabilities, for advice and assistance. We developed a list of experts that knew about inclusive education and asked them for advice and commitment to help in whatever way they could. Calls were made to the Department of Education for their ruling on the right of a parent to request inclusive education for their children with disabilities and the school board for the formal appeal process. Linda contacted her church for support and asked friends to write letters that discussed their views on Paul going to school with their children.

Much had happened in two weeks. We had traveled via the telephone lines from Vancouver to Toronto gathering advice and assistance. Many phone calls had been made and much talk had occurred during these two weeks.

Two Weeks Later...

We gathered at Linda's house to debrief and share what we had learned and collected during the past two weeks. It became very obvious early in the process of supporting Linda and her son "(t)he voluntary sector faces an opponent which is paid to maintain the status quo" (Le Gras, 1984, p. 146). The sheer volume of "grunt work" was overwhelming. The number of phone calls, locating of resources and making sure everyone did what they had to do was exhausting. It was going to be tough to accomplish our goal by doing it primarily with volunteer hours.

Maybe They Will Say Yes if We Ask Once More

It was decided to schedule a face-to-face meeting with the school board's senior staff, Linda and an advocate from the support group. We hoped if Linda, with her advocate, had a persuasive conversation in an interpersonal exchange (Klandermans, 1992) with the senior staff they might reconsider once they learned she had sought support.

I remember hoping this meeting would solve the problem. The Board would clearly see Linda was going to be persistent and that she now had a group of people behind her. Therefore, it was best to support her request. The Board I worked for had supported parental request when they presented their wishes with an advocate. We were sure this Board would respond similarly now that they saw Linda was not going to budge.

The meeting took place two days later and was followed up with a letter the next day from the senior staff.

> *Dear Mrs. ________,*
>
> *... I must inform you that your request for a placement for your son Paul at _______School in a fully integrated setting is being denied. ... Although in principle, we are very supportive of providing for the instructional needs of special needs youngsters in as normal an environment as possible, we feel that the grade ______ would not be appropriate at this time. (Letter, September 21, 1988)*

Crushed

> It should be no surprise, ... that most grassroots activists run into resistance that seems unreasonable and sometimes even mean-spirited. ...you will probably encounter someone – a group of people or an institution – who opposes your solution and resists your efforts. (Dingerson & Hay, 1998, p. 17)

We were devastated from the rejection but Linda would not be swayed. She was clear about what she wanted. She wanted to appeal the district's senior staff's decision.

> *Dear Senior Staff,*
>
> *We are appealing your decision to deny our son an integrated education at _____________ School. (Letter, September 27, 1988)*

Preparation for the Appeal

We had so much to do. The needs were great. It required approaching the situation on a number of fronts. We needed to mobilize our resources (Oliver & Marwell, 1992; Zald & McCarthy, 1979). Although there were specific tasks to be done for the appeal, we also believed it was important to work at other levels that might externally influence the formal appeal procedure. Saul Alinsky, a well know community organizer, cited in Le Gras (1984) says, "(t)he organizer simultaneously carries on many functions as (she) analyzes, attacks, and disrupts the prevailing power pattern" (p. 34). This speaks to what needed to happen if we were to get Paul into his neighbourhood school. We needed to use multiple strategies to secure inclusive education for Paul.

Developing Further Allies

We talked about continuing to develop allies. Others noted networking with personal contacts as contributing to successful advocacy (Lahr & Brotherson, 1996). We knew that each ally we contacted the previous two weeks had friends, neighbours, acquaintances and coworkers. We needed to keep looking for allies and this was best done by talking about Linda's situation with as many people as we could.

National Public Support

CACL's national conference was to be held in two weeks in another part of the country. It was decided that this event would be used to distribute information sheets about Linda's situation and to secure support through a letter writing campaign. By making Paul's situation public at the conference we were able to rally support in a way that would have been simply too expensive to achieve through other means.

> *Dear School Board,*
>
> *Our association has worked closely with the School District in _____________ to support integration and feel that valuable lessons can be learned from this experience. We hope that you will reconsider the placement of Paul into a regular classroom. We understand that some of his friends already wish that he were going to their school.*
>
> *(Letter, October 14, 1988)*

We learned from this tactic that the grapevine goes both ways. The Board heard about the letter writing campaign long before they received any letters. The energy the Board put into trying to find out who presented the family's plight at the conference surprised us.

The Board's insistence to learn who spoke publicly caused me great concern. This concern came from the fact that it was I who shared Paul's situation at the conference in a session I presented about the status of inclusive education in Alberta. I was stunned by their response. I was extremely naïve in believing my actions would have no ripple effect.

I think I had the sense of protection from backlash because I was discussing the situation publicly in another province. I was to learn that distance did not safeguard me.

During numerous phone calls, the Board's senior staff requested that Linda name the people that shared publicly her dispute with their board. They were adamant in stating to Linda that she had no right discussing this appeal with others and that they would not tolerate such public distribution of information. Linda remained calm throughout the calls and informed them that she had given her permission for her situation to be discussed and that she would continue to use whatever strategy she wished to make her situation public.

The Board's personnel were not satisfied with Linda's refusal to give names and they continued to try to gain this information by calling the Alberta Association and Canadian Association for Community Living.

I was relieved to find out that the associations did not feel that this was information that they needed to locate for the school board.

As Le Gras (1984) writes,

> (d)irect action, ...involves risks of a similar kind. Where laws are not broken, social codes usually are and activists face hostility and danger. An individual alone can engage in direct action. However, most often, small groups are involved for reason of support. Activists also realize the power of collective action when peeling away the cover of silence. (p. 28)

This situation highlighted that our actions could cause hostility and danger for the members in the support group and we needed to consider safeguarding members from being personally attacked. The actions of one member were to be viewed as the action of the group and responded to in this fashion when hostility from the outside occurred.

Throughout this period of inquisition I was extremely disturbed. I was concerned about what would happen if they did secure this information and what would they do with it. But on the other hand it felt cathartic to name out loud what Linda and Paul were being refused. If they lived in another part of the province or country their request for inclusive education would be granted. Without talking about their circumstances we would never change the situation. Out of this struggle I became even stronger in my resolve.

Considering the backlash and flood of opposition from the senior staff we considered this to be a successful strategy (Lewis & Barnsley, 1990) in raising awareness of Linda's situation and gathering support.

Church Connection

Linda met with her pastor to ask for his support. He was not supportive and indicated to Linda that he did not see it as his job to get involved. This caused her great pain. Linda's religious beliefs were intertwined with her understanding of her child's rejection and she felt that her church should be on the side of questioning Paul's exclusion. This set of beliefs were similar to those of Catholics in Latin America that "argued that the church should be on the side of the oppressed in this life as opposed to simply promising them an eternal reward after a life of suffering" (Hamilton, 1996, p. 29). As this complex belief contributed to widespread forms of social protest in Latin America, Linda's religious beliefs were at the heart of her struggle for Paul's acceptance.

To help Linda try and connect her pastor to her plight we contacted an advocate for inclusive education that lived in Toronto. He was a minister and was active in advocating for inclusive education. We asked him for advice on ways to connect Linda's desire to have Paul included in his neighbourhood school to the church's belief about people with disabilities and what it meant to be a welcoming religious community. We asked if Linda's minister could contact him to learn how he could support Linda in her quest to have her son included.

Research

We completed a literature review. We collected and organized articles that talked about the benefits of inclusive education for children both with and without a disability and how to include children in regular education classrooms. We developed a class profile of expectations in a Grade 6 class and showed how Paul's learning style and needs could be accommodated in the regular classroom.

Ferree and Hess (1985) state that in a social movement in addition to specific skills and material objects needed for effective action "an ideology, or a way of explaining reality that makes sense to potential participants and justifies their involvement" (p. 26) is equally important. The results from the literature search on inclusive education were used to validate our position to the school employees and to gain new recruits to Linda's cause.

If Need Be, Get an Independent Evaluation

We thought an assessment by a psychologist describing how Paul could be included would be helpful. However, this strategy backfired. When the psychologist was contracted, we were not clear about what we were looking for. In the report, the psychologist described how Paul could be educated in a regular class, but he also reported Paul's IQ scores. The school board had used Paul's IQ as a reason for his exclusion from his neighbourhood school. When the Board reviewed our independent assessment they ignored the portion that spoke to how Paul could be accommodated in the regular classroom and zeroed in on his IQ score. This traditional special education approach of using IQ scores to categorize and separate children for education was at the heart of the school board's argument to exclude Paul. They used our assessment against us by saying that our psychologist also stated that Paul's IQ was such that he could not handle the regular classroom.

Political Connection

Linda contacted her school trustees and asked friends to do the same. She was willing to ask as many people as she could to help. In addition to the trustees, Linda wrote to the Minister of Education to keep him abreast of her situation.

> *Dear Minister of Education,*
>
> *This is to inform you of my difficulty in getting my son Paul into his neighbourhood school.... We are currently appealing the decision of the ____________ School Board. Paul at this time is not in school because he is being denied access to his own neighbourhood school.* (Letter, September 27, 1988)

Neighbours and Friends

Linda continued to ask friends to give testimony about how they viewed Paul fitting in with his peers in the neighbourhood. She asked them to write why they wanted Paul to go to school with their children and what benefits they saw for both Paul and their children.

> *Dear School Board,*
>
> *... I cannot understand how our school system can fail a child such as this. The attitude of some associated with the school is quite frankly, cruel and not worthy of one of the most enlightened countries in the world. ... I sincerely hope you will re-evaluate your*

> *program for handicapped children. Especially those that so obviously have the capacity to learn.* (Letter, October 14, 1988)

I was taken aback by the number of people who were eager to help after they heard Linda's story. I noticed that when Linda talked about her situation people often responded by sharing their own stories of rejection or their children's stories of rejection in relation to schools. The telling of Linda's story seemed to bring to the foreground listener's stories of similar experiences. There was a sense of solidarity as they told each other their stories.

Another Family's Struggle

In our quest for information we become aware of a family in another city in Alberta that appealed their Board's placement decision for their child. After a long struggle this child was now attending his neighbourhood school. We contacted them to get whatever written documentation they might have that would help Linda in her appeal.

Moral Support and Assurance

We encouraged families and friends to call Linda to assure her that she was doing the right thing and that there were many people cheering for her and her son. This seemed very important to Linda. She told us weekly who called and from where. We encouraged friends from across the country to make contact with Linda via the telephone or by sending her a note. We knew it was important that she knew other parents admired her strength to appeal the Board's decision.

Persistence

There was so much to do and so little time. The fact that normal life duty needed to be attended to made all of us tired but did not weaken our resolve. We were not afraid to look around us, look again and look harder to find an avenue to help Linda achieve inclusive education for Paul. We did not allow the stress of time to prevent us from being continually creative in seeking support in as many places as possible. We talked always of what needed to be done immediately and what could be addressed at another point in time. Nothing was not worth exploring. There was always someone at the 'kitchen table' that would offer to do the work.

Parents' Right to See Records

The next difficulty was trying to access Paul's school records. This took numerous phone calls and a visit by Linda to the school board office. This was a tiresome task that was not very informative. After many non-returned phone calls from student services Linda went to the school board office and stated that she would not leave until she was given access to her child's file. After a long wait a consultant was made available to review Paul's file with Linda. The psychologist informed Linda that she could not give her the information that was in her son's file without permission from all the testers. She then implied to Linda that she would not gather any worthy information from the reports and would only provide Linda with the raw scores of tests written on a piece of paper. Although Linda continued to insist she wanted to see the whole file the consultant refused to give her access.

While Linda fought for access to her child's file the appeal panel appointed to hear her case was given an array of reports from early childhood checklists to school reports to assist them in making their decision. Linda was not to see what the appeal panel received until a number of weeks after the appeal hearing and then only after she gained legal counsel. In this situation she was denied the opportunity to properly prepare and respond to the information the appeal panel would rely on to support their position (Learning Disabilities Association of Canada, 1993). Control and domination is exerted over those who are oppressed, typically through "... the retention and control of information and knowledge" (Giddens, 1993, p. 188).

I had no idea how to go about arguing Linda's right to view her child's file. I knew it was wrong that Linda was being denied full access to the contents but was not clear how to dispute the board staff's refusal to give her the information she requested.

Supporters

The appeal procedure policy stated that parents had the right to be accompanied by a single advocate (at their expense) at the appeal hearing. This seemed unfair. Linda felt she needed the support of more individuals to present her case. Linda wrote to the Superintendent stating that she wished to bring a number of experts to the appeal. The Superintendent responded with,

> *Dear Mrs. __________,*
>
> *In response to your request to bring more than one advocate.... Please be informed that only one advocate will be allowed. It has been the procedure of the ____________ board to allow only one advocate to be present... And in all fairness to other parties that have made presentations to the committee we will abide by this procedure.* (Letter, October 11, 1988)

One more request denied. However, we were not willing to stop at no. Linda wrote back. She said that because English was her second language, she wanted the right to have a friend present to translate. In addition, she wanted the appeal hearing taped. Both requests were agreed to.

Impartial Appeal Committee Members

Linda was informed, prior to the meeting, who the Superintendent appointed to the review committee. In this step of the appeal, the Superintendent appointed a Student Placement Review Committee consisting of a physician, psychologist and one other person. None may be staff of the school board.

From the support group's point of view there was nothing impartial about the committee members. The members were all well known in their fields and openly supported the status quo of the school system's delivery of education for children with disabilities. That was segregation. One of the panel members had been the co-signing psychologist of a test that was being used by the Board to support their view that Paul should remain in a segregated class. Another member had her child placed in a private special education school that this Board paid to provide services. We wondered whether this was a conflict of interest. At the time we did not understand our right to question this (Learning Disabilities Association of Canada, 1993).

Discord in Support Group

In addition to dealing with the appeal to the Board, the Board's response to the public presentation and the need to gather more support, the group was faced with internal conflict. A member of the support group felt we had made the wrong decision in deciding who should attend the appeal meeting with Linda. In an effort to change the group's decision the individual contacted our supporters as well as senior staff with the school board to gather support for her position.

It was necessary to deal with the internal conflict and to resolve it as soon as possible so not to jeopardize Linda's situation and the IA group's integrity from which the support group was formed. We had a meeting with the IA Executive. The purpose was to establish ground rules for support groups connected to the association. The key purpose of a support group was to support the parent(s) and child. Support group members' needs were secondary. In addition, once a group decision was made the members were then required to speak with one voice. If this was not satisfactory to any member of a support group then it was incumbent upon them to withdraw from the group. In addition, to clarify IA's position on the role of a support group, we made numerous phone calls to our supporters and the school board to clarify Linda's decision as to who would attend with her and to assure others that the internal problem had been rectified.

This situation was devastating to Linda. I knew Linda looked up to the person who created the discord and she was taken aback by her behaviour and was wounded by this member's actions. In addition to the stress of fighting the Board she was also exposed to the conflict within the group.

Appeal Meeting

The day finally arrived. Linda attended the meeting with two members from the support group and Paul. They faced an appeal panel of three that would decide Paul's fate.

The Board presented first. They gave their rationale for why they believed Paul should remain in the segregated classroom. Linda spoke second, once again stating why she wanted Paul in his neighbourhood school. The appeal hearing provided no new insights.

Appeal Committee Recommendations

The response had come on October 31.

> *Dear Mrs. ___________,*
>
> *The committee has recommended that Paul continue in the segregated program at ______________________. It is further recommended (by the appeal committee) that we attempt partial integration for perhaps one day a week at his neighbourhood school on a trial basis. I do not feel that such a disruption in Paul's program is in his best interest....*
>
> (Letter, October 31, 1988)

Regrouping

The group gathered one week later to debrief. Linda shared that she felt the appeal panel had discussed her case prior to the appeal hearing. They stood in the room together when Linda arrived with her supporters. Although the panel members verbally welcomed Linda, she and her supporters were required to make their own way to their seats. Linda felt the sense of "them" and "us" before the meeting started.

To Linda, the meeting was formal and intimidating. Linda's supporter had stated this to the committee.

> *... that Mrs. ___________ felt intimidated and frightened by the Hearing. She felt that she should have had expert people with her. Dr. _________ explained the process of the hearing and stated it was not a trial but an impartial hearing and that their recommendations would go to the Superintendent.* (Appeal Hearing Minutes, October 19, 1988)

The chairperson then stated that either Linda or her supporter could speak to Linda's case but not both of them.

We talked about what we could have done differently. Upon reflection we felt that we should have prepared a formal presentation. An outline would have been helpful to ensure all of Linda's lines of reasoning were covered. The feeling was that this was an unfair process. Linda was limited to who she could bring and therefore her case was not adequately presented. The appeal was intimidating. As a parent Linda had limited resources and expertise and was expected to plead her case to a Board with virtually unlimited resources.

This meeting was very difficult for all of us. We spent much of the time second-guessing what we had done to date. We believed the appeal meeting would be fairly constructed. It was if the appeal panel saw Paul and Linda's experiences as if they were

> Living in the blank spaces, the margin, or even off the page, their images have not been considered subject for regard or reflection. Their lives have been in the world of marginalia, little penciled notes at the edge of cultural texts. (Smith, 1999, p. 133)

What Next?

We questioned if we should go to the next level. Do we re-appeal? Who can apply pressure? How do we get money to secure legal assistance? Who do we talk to? The collective was tired, depressed, angry and filled with anxiety. We felt defeated and did not know what to do next. However, to focus we once again asked, "What do you want Linda?" She was clear. She wanted Paul to go to his neighbourhood school.

We had no choice. We needed to forge ahead.

Looking Again, Looking Harder

We needed to know what the next steps were in the appeal process and how much time Linda had before she informed the Board that she would appeal the decision. A face-to-face meeting with the student service supervisor was arranged because there were a number of questions we had that would be best answered in this fashion.

AACL and CACL were contacted again for more formal support. They were the ideal organizations to go to for financial help because they were part of the group's social network that consisted of people already linked by our shared interest for inclusive education. There was a pre-existing basis for sympathy to our emerging need for assistance (Ferree & Hess, 1985). Both associations were willing to provide legal advice. In addition to legal assistance AACL provided staff support from one of their community advocates.

Where is Paul?

While we were helping Linda, Paul was still at home without any schooling. As we prepared for the next level of the appeal we also needed to help Paul to continue to learn. This was not going to be a battle won in a short time. We chose two avenues to pursue. These were to request that AACL pay for a tutor for Paul and to access a community college student in a Rehabilitation Program to complete their practicum teaching Paul.

AACL made money available to hire a tutor until a student practicum could start. The college agreed to have a student complete their practicum work with Paul. The only stipulation the college had was the student needed someone to supervise them. I agreed to do this.

This support offered by AACL, CACL and the college helped to strengthen us. We were beginning to renew our forces and had a new set of allies in place to go to the next level of appeal.

Paul was home throughout these initial stages of dispute with the school board. I was often concerned with what he was making of this situation and the number of people *that converged upon his house each week speaking his name. Linda tried to shield Paul from much of the discussion. However, he was in the house and we had no idea what he was experiencing if and when he caught parts of the conversations that were exploring his fate.*

I was equally concerned with Paul's educational needs. Linda and I talked each week about ways she could maintain Paul's learning. This was not something Linda found easy to do. English was not Linda's first language and she felt inadequate in helping Paul maintain some form of home schooling without assistance. I tried to provide simple tasks she could expect from Paul each day but I felt torn knowing that this was a stress on Linda as she juggled the advocacy tasks she took on each week. It was imperative that we find help for Linda with keeping Paul engaged in active learning each day. My energy was better spent securing home support for Paul than in trying to coach Linda on ways to give Paul meaningful learning tasks.

Government's Watchful Eye

Linda maintained communication with the Minister of Education. She received a letter from him stating,

> *A staff member of the __________ Regional Office of Education discussed your concern with Mr. ______, who informed us that you were able to appeal Paul's placement to an independent appeal committee on October 19, 1988.*
>
> *... If you did not agree with this decision, you may then appeal to the Board. If you believe that a fair process of appeal has not been provided to you, you may appeal to me. Please note, however, that the Minister's role in this instance is simply to ensure that you*

> *have access to a fair hearing. The decision on the appropriateness of Paul's educational placement is the responsibility of the school board.* (Letter, November 29, 1988)

Pressure

As we were regrouping we had yet to decide when we would inform the Board that Linda intended to appeal the panel's decision. A letter from the Board senior staff pushed us to respond.

> *Dear Mrs. _____,*
>
> *In the best interest of Paul's education, we feel it necessary to have the matter of Paul's educational placement settled as quickly as possible. ... Pending your request for a further appeal I have arranged to have the school district homebound teacher visit Paul at home to help to maintain some educational progress.*
>
> *Since you have not, to this date, formally written to the Superintendent requesting an appeal to the Board of Trustees, we would like to advise you that if you have not pursued this matter by 1988 12 07, it will be our expectation that you will be in compliance with the direction provided to you by the Superintendent in the letter dated 1988 10 31.*
>
> (Letter, November 30, 1988)

This letter added to our stress. We were feeling at a loss not knowing what to do next. The Board's demand that we respond added to our doubts of our ability to determine our next move. If the Board was so concerned with Paul's education why were they fighting Linda? If they put this much energy into figuring out how to include Paul in his neighbourhood school we would have had the problem solved. I felt we had Paul's best interests in mind, and because of this, we were cautious about going to the next step. We did not feel ready to respond. We did not want to lose at the next level. We were *finding our way. There was a need on our part to have more in place before we indicated our intentions. The letter forced us to state our intentions. To respond before we were ready added to our distress. At this point we still had the sense that we must follow the Board's imposed timelines and could not set ones that met our needs.*

Response

> *Dear Superintendent,*
>
> *.... Please be informed I wish to appeal the decision of the panel, which convened October 19, 1988.* (Letter, December 3, 1988)

A date was set for December 19.

We were worried about this next level of appeal. Would it be more of the same? Would we really be heard? Would Linda's perspective be taken into consideration? We would not be going into this appeal as naïve as we were the last time but we were also not sure we would be able to take on the established Board's institutional expert perspective of what education was for children with disabilities.

We were very weary at this point in time. We had had offers of support from AACL and CACL but we had not acted formally upon these offers of support. We needed more recruits to continue the battle in which we were immersed. *In some ways this was hard because we had to admit to ourselves that we could not do it alone. The group of volunteer advocates that had a vision for inclusion needed more formal support in what seemed to be a David and Goliath battle. We sought help.*

Preparing for Next Level of Appeal

A letter was written to the Board stating that Linda felt the appeal procedure to date had been an unfair process and listed what she expected from the Board prior to the next appeal meeting. This included clarification of the procedures, access to all written documentation the Board received, complete access to her son's file, right to bring counsel and any others she wished to the hearing and a deadline as to when their response was required to give her sufficient time to prepare.

> *Dear Mrs. _______*
>
> *The appeal to this committee is very similar to the independent Appeal Hearing that was held previously. .... As at the previous Hearing, you may have one advocate and an interpreter present. You may also have legal counsel present, but if you choose to do this, we must be informed immediately in order that the district may have sufficient time to arrange to have counsel in attendance also.... Please note that while your husband and son are welcomed to be in attendance, other family members and friends are not invited. ... Please be advised that the Appeal Committee's decision will be made with Paul's educational interest being the major factor.* (Letter, December 14, 1988)

A Whirlwind Support Group Meeting

The response to our most recent call for help to AACL and CACL was access to legal advice. We had three lawyers participate in the December 15 support group meeting. One lawyer was from our city, another had flown in from Toronto and the third was on the telephone from another major city. Each group wanted their own legal council to participate.

The meeting began by updating the lawyers on the status of Linda and Paul's situation. There was much to say. We all added our thoughts and comments as we shaped what Linda had gone through.

Upon hearing the history the lawyers began to discuss their read of the situation. The lawyers exchanged comments in a whirlwind. It was hard for the group to follow all the legal language they used. Linda's stress level was apparent, as she could not remain seated while the lawyers debated what had happened and what should happen next.

Watching Linda through this meeting was like watching a roller coaster. She was up and down in and out of the room. She seemed never to sit longer than a minute. She busied herself at the food table or in the kitchen making more coffee. Her constant movement made me nervous. We had worked hard to keep Linda central to all discussions. Her absence from the room was of concern especially when we would talk about strategies that needed Linda's approval or input. I remember at one point going into the kitchen and offering to do what she was doing so she could rejoin the discussion. I was unsuccessful in convincing her to join the group. I was uncomfortable throughout the meeting because Linda was so distant from us.

She seemed so vulnerable that evening. Up to this point I had seen her as someone who picked herself up and put on a strong face and went ahead no matter what. When I look back on this evening I was not sensitive to what this was like for Linda and her family. I focused on the issue of getting a child into his neighbourhood school but not on the hurt Linda must have felt. Linda saw her son as a normal child first, who just happened to have a disability layered over his normalcy. She had to go through so much to get what other parents take for granted for their children; an opportunity to belong; to become a welcomed part of the neighbourhood school. It mattered to her where Paul went to school. This battle hurt. I began to see it as a wounding process for Linda.

I was to learn later, Linda, who was a well-organized individual, had not begun her Christmas shopping at the time of the meeting with the lawyers. This was the second week of December. It was not until a few days before Christmas that she finally completed this task. This appeal was taking its toll on Linda.

The lawyers talked about the gross unfairness, how the appeal procedure did not start out fair, and how Linda should have been given the right to bring evidence. They questioned if the appeal panel was impartial, if it acted in a reasonable way, if it was an independent judgment. They commented that this could not be seen as a fair appeal so we should appeal again before going to the Board. They questioned the panel selection procedure. Linda should have been able to select one member, the Board select one and then they should select a jointly agreed upon member. They said we should go to court and ask for a judicial review of the appeal process and to the minister to state that the procedure was not fair. To the lawyers it was fundamentally unfair to have to go through so many hoops. They thought we could use the new Education Act, which allowed the Minister of Education to overrule student placement decisions made by a school board.

New ideas were flowing. The list of new tasks to be accomplished was extensive. Included among them were contacting MLAs, setting up a meeting with the Minister of Education, making a presentation to the Board and principals about inclusion, challenging the Board's materials, using media to publicize the situation, and involving Paul in other community activities to keep him connected.

The lawyers challenged much of what had transpired to date in relation to the Board's response to Linda's request and decided that a letter stating this along with indicating Linda would not be attending the appeal meeting set for December 19 was the next necessary step. This was the most radical action we had done to date. We had been responding to the Board rather than taking control of the process. The legal members of the team brought new life to the group and we felt in control for the first time.

My head was spinning. Three lawyers were each trying to outdo the other while the support group sat trying to grasp all they were suggesting and how we would go about doing this. The meeting went on for three hours. I was exhausted by the many ideas.

The presence of the lawyers evoked different feelings. In some ways I felt an explosion of confidence. We were in charge. We could reject the deadlines imposed by the school board with the support of the lawyers' legal perspective on the case. We could make our own demands on the Board expecting clarification of the appeal procedure. We could impose our own deadlines. We had been dancing to the tune of the Board rather than imposing expectations on the Board.

However, with the sense of confidence, I also had a feeling of losing control. We were now in an arena that was not our domain. The lawyers were in control; it was their territory we were entering. As we gained support from the various advocacy groups it came with strings attached. Each group had their expectations and demands that they placed upon the support group. There were political struggles between the national association and the provincial association as to who was in control. This brought a new dimension to the advocacy efforts.

We were moving away from our grassroots group and handing over the decision-making to the professionals. The professional knowledge came not only from the legal counsel but also from the institutionalized advocacy consultants. Though they had *knowledge, I struggled with the idea that we had the local knowledge. We understood the context and we were the physical support to Linda. This was important not to lose because in many ways we were the doers. The ideas were of no value without the people to act upon them. As ideas were being generated it required those of us who sat at the kitchen table to act upon the suggestions. We were a small group and the professionals seemed oblivious to this. They set the stage and we were expected to act upon the directions. So much was required to create continued community support and shape the dialogue in Linda and Paul's favour. I often wondered how we would accomplish everything. Exhaustion was mixed with commitment to Linda and Paul. So many directions, so few people, so little time. How could we keep up this pace?*

The Legal Battle Begins

A letter was sent from Linda's lawyer to the Board stating her position.

> *Dear Chairman of the Board,*
>
> *... respectfully request that the appeal hearing be cancelled.*
>
> *I have reviewed some of the proceedings to date with Mrs. _______ and, to be frank, I am dismayed at the unfairness of the hearing to which she was subjected by the Appeal Committee on October 19, 1988. In my view, the hearing did not meet the fairness requirements of either the guidelines set out by the Minister of Education in December 1984 or the common law...* (Letter, December 19, 1988)

The letter was scheduled to arrive at the school board before the scheduled appeal hearing. This turned out not to be the case and Linda was called at home on December 19 to request why she was not present. She replied that her lawyer had forwarded a letter on her behalf indicating she would not be present.

The Board retained a lawyer and she responded to Linda's lawyer's letter.

> *Dear __________,*
>
> *The writer has been retained as the legal counsel for the _________board with the respect to the appeal by your client Linda __________, from the placement decision for her son, Paul ________.*
>
> *I anticipate having sufficient information to respond to your letter within the next week. In the interim, enclosed is a copy of the minutes of the Board Appeal Committee meeting on December 19, 1988.* (Letter, December 30, 1988)

Minutes from the appeal meeting that Linda did not attend were included with the Board's lawyer's response to Linda's lawyer's letter.

> *The above people were present (school trustees) at 4:30 p.m., however Mrs. _______ was not in attendance. At 4:40 p.m. Mrs. ______ was called at her home and she stated that she would not be present and had we not received a letter that had been sent to the ______Board that day. She was informed that the committee had not received a letter. Two letters were located at approximately 5:00 p.m., addressed to _____ from Mrs. ______solicitor requesting that the appeal hearing be rescheduled.* (Minutes: Board of Trustee Appeal Hearing for Students with Special Needs, December 19, 1988)

Linda was very disturbed by her letter arriving late at the school board office. Not giving the committee members sufficient time to learn that she did not plan to attend was very distressing to her. This was an unpleasant experience for her and she worried that this would jeopardize her situation in the eyes of the school board members. She did not wish to antagonize them.

Quiet on the Front

There was no further correspondence between the Board's legal counsel and Linda's legal counsel. The ball was in our court. The support group met in mid-January. We were anxious to know what the next steps were. We had grown accustomed to discussing more frequent interactions between Linda and the Board.

In some ways the slower pace was helpful. The struggle was draining for Linda as well as exhausting for the support group members. The time between the pre-Christmas meeting and the January meeting allowed everyone to take a break, gather their strength and get ready for the next advance.

Work Never Ends

Although it was quiet on the front we had not stopped working.

Our lawyers questioned whom the Board retained as a lawyer because she worked for the Alberta Association of Trustees. Her letterhead stated that affiliation. It was decided a letter would be written to determine whether she was representing the Association or the Board.

Home instruction was finally in place. The second week after the holidays, the Board sent a homebound teacher to meet with Paul. Linda asked her to prepare a list of learning activities for Paul to complete with the community college student who had started the week before. The teacher left without doing this. A date was set for me to meet with the practicum student to design an education plan for Paul. Linda shared that Paul was happier now that he was working with the practicum student.

Linda sent a letter to the Minister of Education requesting a meeting. When she called the Minister's office to follow up on the letter she was informed that they had not received a letter from her. She hand delivered another letter and there had still been no response. It was decided a phone call from someone from the Minister's constituency was in order. If there was no response to this phone call, then Linda would write a letter to the Minister stating all the attempts she had made to contact him.

In our attempts to keep reaching out to gain support it was decided to try and gain the support of Linda's church minister again. A meeting was set with Linda and another parishioner from the support group to meet with her minister.

We decided to seek a meeting with the president of the school's parent group to gain support from that community. The president had written a letter in support of Paul attending his neighbourhood school. Linda knew the president personally. We also planned to invite the parents from the school group to attend one of our support meetings or fundraising social events to understand what we were trying to accomplish for Paul. Through these visible events (Oliver & Marwell, 1992) we could invite others to participate in supporting Linda.

More work needed to be done to connect Paul to his community. We needed to find out what youth did in the community after school and to get Paul registered in these activities. Paul and the practicum student would take walks to the school during recess time so he could see his friends. The president of the parent group would be approached to see if her daughter, who was in Grade 6, would be willing to introduce Paul to her friends when he was at the school playground. Linda would work on inviting friends after school to hang out with Paul.

A letter had gone to Linda's MLA asking for his support. A follow up call would occur if she had not heard from him in a week.

Further work on reviewing the research on inclusive education was being completed by a student from the University of Alberta. He was compiling a literature review that included an annotated bibliography. The student was contacted to get the draft and the final copy when it was completed.

Media was not yet contacted. We were still leery about going public. It was decided to use the internal written communication forms that IA, AACL, and CACL had in place to raise our memberships' awareness of Paul and Linda's situation and to gain further support.

A phone call needed to be made to the Psychologist Association of Alberta to clarify a point of conflict. The chair of the October appeal panel, in which he was supposed to be an impartial party, used a report as evidence to exclude Paul from his neighbourhood school that had his signature as the supervising psychologist. We wondered if this placed him in a conflict of interest.

Two conferences on the topic of inclusive education were planned for in the city in March and June. We would encourage the Board's senior staff and school staff to attend.

The suggestions and expectations generated with the new advisors overwhelmed us. There were more ideas generated than we could physically follow up. However, we knew it was important to do as much as we could to keep up the pressure and to continually think of new ways to approach the situation. Each idea was valuable but required time and human resources. I felt a real sense of responsibility to capture all that was being suggested and to ensure that we made an effort to make it happen. There just was never enough time. As we got a handle on some of the suggestions we needed to do *more would be generated. The list never seemed to get smaller. The feeling of being overwhelmed never seemed to go away.*

Retaliation

The Board's lawyer finally responded to Linda's lawyer's letter dated December 19. The Board's lawyer said that, in her view, the letter formed the basis for a defamation action because of the wide circulation of the letter. Linda's lawyer's letter had been sent to all parties supporting her. As well the letter named specific senior staff and indicated that in the lawyer's opinion the members of the appeal panel had not treated Linda fairly. The Board's lawyer's letter countered every item and challenged Linda's lawyer's interpretation of what had transpired. In addition to countering each of Linda's lawyer's points, the Board's lawyer requested a written apology.

The Board's letter stated that:

> *As long as Mrs. _________ insists on keeping Paul from attending school, his education is placed in jeopardy.* (Letter, January 18, 1989)

This letter was unnerving and felt very heavy-handed. My naïve understanding of legal process created turmoil for me. Although the lawyers reassured us that this was due course, it seemed very serious and I felt intimidated. I keep asking myself, "What have we gotten into?" I was losing sleep over the letters.

I remember being extremely concerned for Linda's well being when she received this letter. Linda's husband worked out of town for long periods of time. He had been in town when this letter arrived. He began to doubt that the struggle was worth it. He too was asking the question, "What have we gotten into?" Linda was extremely distressed.

She was not willing to abandon the struggle but was concerned about the financial cost and further disruption to her family life.

The support group continued to gain assurance from the advocacy groups that they would support Linda financially during the legal battle. This helped alleviate Linda's family concern and the support group's concern. Without these financial resources it would have been prohibitive for the family and the support group to engage legal counsel.

Counter Attack

Linda's lawyer responded to the Board's letter by questioning if the lawyer was in a position of conflict of interest because the Trustees' Association also retained her. How could she represent a single board in this case? He also indicated that a reply to her allegations would arrive in due course.

What had all this to do with getting a little boy into school? The path seemed to be veering off in a different direction. I understood the purpose of this sparring but was stressed by what Linda was experiencing as she received these letters. This was not something we had had a sense of when we started this appeal. As a teacher I was concerned with my ethical responsibility to my profession. Linda's lawyer was questioning the professional conduct of educators. Where did this place me within my professional code of ethics? I did not feel at ease as the lawyers began to critique, in public forums, the skill and integrity of other educators.

Responding to Conflict of Interest

The Board's lawyer clarified how the arrangement worked between the Board and the Trustees' Association and hoped that her explanation would allay any fears or questions Linda's lawyer had regarding her involvement in the matter. If he was not in agreement with her involvement she suggested he approach the Law Society to determine if the arrangement which the Alberta School Trustees' Association had with its member boards was acceptable to the Law Society.

Risk and Faith

Much had happened in a week. We gathered to debrief and plan the next steps. The series of letters were discussed and the lawyers kept assuring us this was typical and we should not be concerned. The content no longer seemed to be focused on Paul and his schooling but rather on establishing the lawyers' positions. Although Linda and her supporters felt that we were at risk, we needed to put our faith in the lawyers. *This was not easy to do. The letters continued to feel very threatening. I was aware that other parental requests for inclusive education for their children with disabilities resulted in formal legal action but had not visualized Linda's case coming to this.*

Support Group Update

A meeting had taken place with Linda's church minister and he was more positive this time. He agreed to talk to the neighbourhood principal and to central office. He suggested Linda speak to the church's women's group for further support. He suggested Paul become part of the youth group. He agreed to speak to the minister in Toronto for advice. He also said he would speak to his friend, a trustee on the school board, and said he would show his support by attending any meetings she wished him to attend.

This renewed support from Linda's minister reminded us of the importance of not sending a parent to a meeting alone. The presence of a friend explaining Linda's need for her minister's involvement helped to make clear for the minister what Linda was seeking.

As well, it demonstrated that Linda was not alone. The minister was one of many players who shaped this plotline of Paul's journey to his neighbourhood school.

Linda had met with the school's parent group and they were open to a presentation on inclusive education at their next parent meeting. *This was exciting. Talking to the parents could help build a stronger base for Linda's position. The next dilemma was who would do this. I did not feel comfortable talking about inclusion at a public meeting. I was too close to the advocacy work to speak publicly. My Board's consultants provided support to this board. I was concerned if I spoke to the group it may be construed as being in conflict. After much talk it was decided that the parents would do the presentation. It seemed appropriate that the session be parent to parent.*

We decided that if we could not get a meeting with the Education Minister, a meeting with the Deputy Minister would still be valuable.

We continued to debate when media should be contacted. We decided to continue to wait.

A letter was to be sent to The Alberta Psychologists' Association to get in writing their ruling on the matter of conflict. In a telephone call the Executive Director confirmed that a psychologist, who had signed an assessment in a supervisory capacity, would be in conflict if said report was used in an appeal in which he was to be an impartial member.

Linda's lawyers planned a meeting with the Board's lawyer in order to discuss the appeal procedure with the trustees. They would negotiate procedure, discuss natural justice and discuss having Paul attend school in a regular classroom until the dispute was settled.

And Yet Another Meeting

The meeting with the Board's lawyer was yet to occur. This would happen by the end of the week.

Linda and a friend met with the church's women's group. The group agreed to put forward a resolution at their annual provincial meeting to support inclusion. An educator who supported inclusion and attended the same church as Linda agreed to make a presentation to the women's group to assist them with forming their resolution.

A meeting had been secured with the Deputy Minister of Education. Linda's minister, along with other members in the support group, would go with her. An outline as to whom and what would be discussed was shared.

It was discussed that we needed to have a legal opinion in place concerning our legal position. The lawyer from Toronto felt that this was necessary because she was concerned that Linda's situation was not as favourable as we all felt. Using the courts could be detrimental. Negotiating with the Board might be advantageous.

The Toronto lawyer was extremely concerned that the Alberta lawyers were not counselling Linda accurately. She felt going to court would be the wrong thing to do and that a legal opinion was necessary to better understand our position. Her insistence added to my level of anxiety. The legal opinion cost money and required further negotiating with AACL and CACL to determine who would pay for this. The lawyers' disagreements added to the work that we needed to do to as we negotiated with the two advocacy groups. There were so many unknowns, so many different opinions.

Biting Chill

February had touched the city with a biting chill and the group was bitterly affected by it. The blizzards caused disruption to our meetings and added to our exhaustion. As if the weather was not bad enough, we had to deal with lawyers' varied advice. There were continual debates among the lawyers as to how to best proceed. Each lawyer had his own views and sometimes they disagreed on the next steps. On some occasions Linda had to decide what to do next after listening to their advice. During the cold storms of February the struggle among the lawyers came to a head.

The lawyers felt Linda needed to decide who her formal legal counsel would be. Up to this point all three lawyers were giving advice. However, in the next level of appeal, the lawyers felt Linda needed to establish one legal counsel. The question was put to Linda to decide who she would like to legally represent her.

After much deliberation between Linda and the support group, Linda decided to work with the lawyer that resided in her city. This was not an easy decision. We needed to deal with the political aspect of which group had provided the lawyer to the support group and to ensure we were not offending anyone. This lawyer was selected because he initially volunteered his time to the support group and had been there from the beginning of the struggle. As well he resided in the same city and this would make it easier to work with him. It was also decided that the other two lawyers would continue to provide advice but that Linda and her chosen legal counsel would make the final decision.

Meeting with the Deputy Minister of Education

The Deputy Minister indicated that he personally favoured inclusion. The Department encouraged integration. He said it was desirable that the decision regarding this matter was made at a local level. He would speak with the Superintendent. He said that because the Minister of Education might have to hear an appeal, he could not meet with Linda.

Laying Out the Procedures

Linda's Alberta lawyers met with the Board's lawyer to lay out the procedural matters in relation to the Board Committee Hearing. Much of what had been challenged and requested on Linda's behalf in previous communications was granted. Linda would be able to prepare her case with necessary resource people present to assist her in addressing her request for Paul to attend his neighbourhood school.

The decision would be made in accordance with the new School Act. This was felt to be in Linda's favour. Under the new School Act, appeals to the Education Minister were allowed on the grounds of substance as well as process.

Cracks in the Armour

During the meeting with the Board's lawyer to discuss procedural matters in preparation for the appeal to the Board, the Board's lawyer stated that the Board was not resistant to inclusion but rather inclusion at the school Linda requested. When this was discussed in the support group, we questioned the Board and their lawyer's definition of inclusion and felt that this needed to be clarified. The Board's lawyer implied Linda could have Paul included if he went to another school and wished Linda's lawyers to clarify this point with her to see if this would be satisfactory.

Linda's lawyers asked if she would be willing to send Paul to another school if he was included in a regular class. Linda said with confidence, " I wish for my son to go to his neighbourhood school so he can become a member of this community." Linda was not willing to compromise on inclusive education, which means attending one's neighbourhood school. The fact the Board was beginning to discuss the possibility of inclusive education was promising.

In the Board's lawyer's follow-up letter confirming the agreed upon procedure for the appeal to the Board of Trustees, she again indicated that the defamatory remarks made in the December 19 letter would be pursued by the Board unless a satisfactory resolution took place. However, the issue would not in any way effect or delay the placement hearing. Linda was also asked to state what her wishes were, in writing, concerning Paul's inclusion.

Linda was continually asked to reaffirm her commitment to Paul attending his neighbourhood school. It was always the professionals that sat around the table and never the parents that asked her that question. I was proud of Linda. Her continual commitment to the idea of inclusion for Paul was a beacon we had all come to count on. As our doubts and exhaustion set in, it was Linda who would pull us back to the issue at hand, that is, making it possible for Paul to go to school with his neighbourhood friends.

Reply

The procedures were agreed upon. Linda provided her wishes, which were:

> *The issue for our client is Paul's integration in the normal stream within a neighbourhood school in order to be among his age peers and friends; academic achievement is secondary. ______ is the neighbourhood school, though it is recognized that integration in that school would take time and planning, Paul is able to walk to that school. _____ is not acceptable for two reasons; it does not go past next term; and our client has lost confidence in the staff there.*

As for the defamation matter, we will propose dealing with this separately and divorced from the other issues as soon as possible. (Letter, February 27, 1989)

In addition to this, Linda's lawyer proposed a meeting between the two parties' legal counsel, Linda, two members of Linda's support group and the school Superintendent with a view to avoid the time and expense of a formal hearing.

During the first appeal the Superintendent was away on a leave. It was the district's Acting Superintendent that supported the first appeal committee's recommendation that Paul remain in a segregated class. The Superintendent had just returned. His return was seen as a window to avoid the formal appeal.

Gathering More Power

A coalition was formed to help raise the profile of inclusive education. We "networked with partners and community members developing a common unity and energy" (Lehr & Brotherson, 1996, p. 354) by inviting associations that advocated for individuals with developmental disabilities to meet in order to discuss what we could do to support each other in securing inclusive education. We met and decided the group would send letters to trustees of the various boards in and around the city. In the invitation letter we introduced the group and stated our wish to make formal presentations to the Board on the topic of inclusion.

The formulation of the Coalition for Inclusive Education had once again placed the actions of the support group in a wider public sphere. My anxiety was once again heightened because of the proposed public activities the coalition would take on. One of the boards that were sent an introduction letter was the board I worked for. Being *involved in the Coalition required me to once again pay attention to which tasks I could participate in as I resided on, and between, the two landscapes.*

Linda had thirteen more letters from neighbourhood members supporting Paul's inclusion at the neighbourhood school. The presentation to the provincial women's group connected to Linda's church was about to happen. We approached the Premier's Council for Persons with Developmental Disability for their support. The student was finished her practicum but continued to support Paul's learning by coming by each evening to give him homework assignments and to correct his work.

Agreement

The Board's lawyer responded to the request for a meeting with the Superintendent.

> *Further to your memorandum of March 8, 1989, I wish to confirm that the meeting in this matter is set for Friday March 17, 1989 at 10:30 a.m. at the office of Dr. ____________, Superintendent of* ______________. (Letter, March 9, 1989)

The Meeting

Present at the meeting were Linda, her translator/friend, Linda's legal counsel, advocate from CACL, Board's legal counsel, and Superintendent.

Legacy of Action

Linda was asked to share what had happened to this point and what she wanted for Paul. She and her supporters wove the journey we had traveled since September 1988. As part of the discussion a clarification of the meaning of inclusion was presented. After hearing Linda's case the Superintendent indicated he would give his recommendations to Linda by April 10.

The supporters at the meeting felt it went well. The Superintendent listened intently and asked insightful questions as he worked to understand Linda's request. The meeting had a different tone and feeling. The decision was now in his hands. Once again it was a waiting game. We could not sit idly. We needed to use the time wisely while we waited for his decision. We hoped for a positive response but we had learned we could not count on it. After all we had had so many rejections. We could not rely on this meeting to be the solution.

Strategizing Never Ends

While we waited for the Superintendent's response the support group continued to follow up on tasks and seek new supports.

The president of CACL would be in town in a few weeks. He was an educator and worked in an inclusive school board. We discussed ways he could help us. We set up meetings for him to talk to key players in the school board, church and community.

AACL had its provincial conference and Linda was invited. The vice-president from CACL was there and spoke to the assembled group about Linda's struggles and introduced her to the group of 350.

CACL ran an article in their national newsletter.

The Coalition for Inclusive Education was preparing to make presentations to a number of school boards. Multiple copies of the book "On Trial" by Jack Batten (1988) were purchased to be given as a gift to each trustee when the group made its presentations. The book highlighted the court case in Nova Scotia of Luke Elwood v. Halifax County-Bedford District School Board in which Luke's family successfully secured an inclusive placement for their son.

The Decision

The Superintendent informed Linda by telephone that Paul could go to his neighbourhood school in the Grade 6 class with the necessary supports for success. He could start in one week's time after Linda met with the Board staff and school staff to discuss his program.

I was elated when I heard the news, while at the same time shocked. It was hard to believe that we finally had a positive decision. It was unbelievable. We had become so accustomed to being rejected. Although it was fantastic that we had been successful the victory felt anti-climatic. It seemed so simple. We had done so much to get to this point. It was over. We had won. We were thrilled. We were exhausted.

Inclusion Makes Strange Bed Fellows

We gathered to share our enthusiasm for the victory. We were also aware to have Paul attend his neighbourhood school, Linda needed to work with the staff that rejected her request and that fought hard against her. As quoted in Bell (1987), Steel illustrates that this was a similar experience of African Americans in their legal hurdles to racial justice in the civil rights movement "... it gave the primary responsibility for achieving educational equality to those who had established the segregated institutions" (p. 60). This would be work for Linda but "in the end, result – not revenge or egotistical self-interest – should be the family's overriding goal" (Munro, 1991, p. 3).

Linda, accompanied by a member of the support group, met with the district staff. The staff was positive and was focused on the job of designing a successful program for Paul. They were professional in their willingness to do as they were directed to do. Linda continued to struggle with having to work with them but, with guidance from the group, she worked well with them to plan for Paul's success.

The support meetings now took a different focus. We worked with Linda over the next few months to help make the transition to the neighbourhood classroom a success for Paul and Linda. We continued to meet on a regular basis. We understood that getting Paul into his neighbourhood school was just the first step in inclusion. Helping Linda to support Paul's new teacher to include him was the focus. *For me this task was most enjoyable because, as a teacher, I was interested in figuring out how to include children. I longed to think about how to support Paul's learning in the regular class. To plan and modify classroom curriculum so Paul could be successful intrigued me. I was excited as I talked with Linda about ways she could coach the teachers to think about how to include Paul in their classrooms. I felt rewarded as Linda shared their willingness to try and help Paul become a member of their class.*

Last Item on the Legal Agenda

> *Concerning the above referenced matter, I'm happy to report that the issue of Paul's placement has been settled through the good offices of Dr. _______ (Superintendent). Paul is now happily attending the neighbourhood school in a fully integrated setting and his progress is remarkable. Allow me to express my gratitude to School District ___ and the Board of Trustees for helping us resolve this matter.*
>
> *At the same time, I take the opportunity to make apology for my misleading statements or derogatory allegations that may have been perceived in the contents of my solicitor's letter sent to you December 19, 1988. I can assure you that there was no intention to impugn the actions or motives of any of the persons named in that letter or of*

anyone else. I regret any discomfort that inadvertently may have been caused by the distribution of that letter. (Letter, May 16, 1989)

Last Item on Paul's Agenda

The opportunity to go to his neighbourhood school gave Paul the possibility to be one of the children. Soon after Paul started attending his neighbourhood school he had many new friends within the community. On a visit to Linda's house I would often greet Paul outside where he was playing with his new friends.

Last Item on the Support Group's Agenda

We celebrated Paul's inclusion in his neighbourhood school but knew this would not be our last struggle. We had started a momentum that we could not stop. We had much to do in laying the foundation for future families to secure inclusive education for their children. We were now less naïve about how easy this would be to accomplish. We were soon called upon to help another family to secure inclusive education for their daughter. We learned much from Paul's situation. We were to learn more as we supported the next family and the many more that came forward in the next ten years. Parents still find their way to my husband and me as we continue our advocacy efforts for children with disabilities to be welcomed members of community schools.

In Conclusion

It took seven months, thousands of volunteer hours and thousands of dollars for legal advice to get Paul into school. Linda's clear vision and determination kept me dedicated and focused to her cause. My commitment to inclusive education grew because of the vision and determination of the parents who joined the group to support Linda.

Linda's desire to have her son included was my first advocacy effort and marked a step forward in my understanding of the struggle for inclusive education. Being directly involved in Linda's support group was at once physically gruelling, emotionally exhausting and politically educational. It is difficult to describe the enormous inspiration that sprang out of Paul successfully starting school at his neighbourhood school. This collective success was to set me on a path towards other advocacy work.

PARENTS REQUESTING INCLUSION: CONSTRUCTING THE INQUIRY

Increasingly I had come to understand that parents of children with developmental disabilities believed their children had the right to learn in regular classrooms (Gill, 1997; Spiegle & van den Pol, 1993; Trainer, 1991; Turnbull & Turnbull, 1996). To secure this educational right, parents were willing to challenge the existing education system (Batten, 1988; Rother, 1996). These parent requests for inclusive education constituted a challenge to the dominant ideology that children with disabilities are best educated in separate classrooms (Jory, 1991). Parents' advocacy for inclusive education plays a role in raising fundamental questions about the meaning and purpose of education for all children and gives notice that education for children with disabilities is under pressure to change. This thrust for educational change for children with developmental disabilities may be described as a social movement (Crichton & Jongbloed, 1998). The inclusion of children with developmental disabilities in local neighbourhood schools requires social change and a shift in societal values.

In my research on the history of education for children with developmental disabilities I had come to understand parents have persisted in pursuing social change and were often successful in advocating for change (Pletsch, 1997). Changes occurred most frequently in education for children with developmental disabilities because parents worked to change the system (Richler, 1991).

DEFINING INCLUSION

Inclusive education is a controversial topic. Discussion about it is confounded because there is no consensus as to the meaning of inclusion. In the literature there are multiple definitions of inclusive education. The following clarifies what I mean by inclusive education. By "inclusion" I mean:

> Maximum opportunity for students with disabilities to be included fully with non-disabled peers in all aspects of school life, using whatever supports are necessary to facilitate social interactions, scholastic achievements, and full membership in the school community. Inclusion abandons the notion of a continuum of educational placements and is based on the presumption that we, as educators, have the knowledge and technology necessary to enable all children to receive an individualized and appropriate education in typical, age-appropriate classrooms. (Connecticut Coalition for Inclusive Education, 1999)

and

> Students are members of chronological age-appropriate general education classrooms in their normal schools of attendance, or in magnet schools or schools of choice when these options exist for students without disabilities. (Neary & Halvorsen, 1999)

and

> In an inclusive school every student is included in regular education and regular classes. An inclusive school also provides all students, within the mainstream,

> appropriate educational programs that are challenging yet geared to their capabilities and needs, and any support and assistance they or their teachers require. (Alberta Education, 1990, p. 3)

and

> ...inclusion is about a philosophy of acceptance; it is about providing a framework within which all children – regardless of the causes of their difficulty – can be valued equally, treated with respect and provided with equal opportunities at school. (Thomas & Davis, 1999, p. 72)

LEGAL FRAMEWORK THROUGH THE 1980S

In June 1987, the Government of Alberta introduced Bill 59, a framework for a new School Act. This legislation set out what the government at the time said would lay a firm new foundation for Alberta's school system that would govern the education system both then and within the 21st century. To advocates for students with developmental disabilities Bill 59 was a threat to uniform, free public education, as we knew it in Alberta because the draft legislation contained a "non-educable clause." The legislation had potentially serious implications for students with developmental disabilities and physical handicaps. Their rights to an education could be taken away from them.

Bill 59 School Act section 29(2) stated,

> A board may, after considering all circumstances respecting the placement of a student in a special education program, decline to provide a special program or any other education program to the student if the board determines that the student is non-educable.

There was extensive public outcry in response to this clause. The government was pressured to review this section. While Bill 59 was being debated the Education Minister published an update which, among other things, made the following reference to section 29(2) in the proposed Bill 59, "In view of the concerns expressed about this section government is carefully reviewing it" (Betkowski, 1988, p. 6). Section 29(2) of Bill 59 was not part of the School Act that was proclaimed in 1988.

Although we had come a long way from the exclusionary policies which continued until the late1970s in Alberta (Carriere v. County of Lamont No. 30, 1978; Cameron, 1979) that kept children with developmental disabilities out of public schools and advocates were successful in defeating the non-educable clause, special education models in the late 80s still did not openly support inclusive education in Alberta.

In the School Act, assented to July 1988, special education programs were referred to in section 29 as follows:

> (1) A board may determine that a student is, by virtue of the student's behavioural, communicational, intellectual, learning or physical characteristics, or a combination of those characteristics, a student in need of a special education program.
>
> (2) A student who is determined by a board to be in need of a special education program is entitled to have access to a special education program provided in accordance with Section 28.
>
> (3) Before a board places a student in a special education program it shall (a) consult with the parent of that student, and (b) where appropriate, consult with the student. (S.A. 1988, Chap. 3.1.29)

The School Act 1988 spoke to a child's right to a special education program but did not prescribe the delivery model for programs. There was no right to regular class placement spelled out in the School Act. The delivery model for meeting the needs of students with developmental disabilities was left up to each school district.

In the1980s parents requesting inclusive education for their children with developmental disabilities were frequently at the mercy of the decision, or whims, of school principals or school boards. Prior to the passing of Bill 59 the School Act did not provide an effective way of helping to resolve disputes. However, the new School Act provided promise. If parental requests for an inclusive placement were denied there would be recourse by appealing the school board's decision to the Minister of Education.

The School Act 1988 section 104 stated,

> (1) A person who may appeal a board decision under section 103 may request in writing that the minister review the decision of the board under section 103 respecting
>
> (a) the placement of a student in a special education program…. (S.A. 1988, Chap. S.1.104)

The year before Linda worked to secure an inclusive education placement for her son, Bill 59, the School Act, had been discussed, debated and finally passed by the Alberta Legislature. Her struggle occurred just on the heels of the new School Act being proclaimed in the Legislature.

TODAY

Ten years later I wonder. Is it different for parents today?

Provincially

Changes to education law and policy affecting individuals with disabilities over the past forty years represents a gradual shift in our society's acceptance of people with disabilities. Gaining the right to public education in the 1950s and 1960s meant children were sent to segregated schools in their communities. Over time education policy changed to allow students with developmental disabilities to be taught in segregated classes in regular schools. More recently we have seen children with developmental disabilities, one by one, being accepted and taught alongside their peers in regular classrooms.

Since Linda's struggle with her school board much has occurred to support inclusive education. Among these is what Alberta Education referred to as a "landmark special education placement decision" in which the minister directed a board to include a child in her neighbourhood school (Alberta Education, 1990). In 1991 the Minister of Education held a forum on special education (Alberta Education, 1991) that recommended that it was necessary for the government to provide support for the process of integration to all involved. In 1993 a policy was set that stated "(e)ducating students with special needs in regular classrooms in neighbourhood or local schools shall be the first placement option considered by school boards, in consultation with students, parents/guardians and school staff" (Alberta Education, 1993). The Alberta Teachers' Association's (1993) policy on the education of special needs students stated their support for inclusive education with the necessary resources in place to support it. The Supreme Court decision on Eaton v. Brant County Board of Education (Rother, 1996) stated that among other things, inclusion of children with disabilities is the norm because of the benefits it generally provides. However, the benefits of inclusion must be assessed on an individual basis.

An ATA Blue Ribbon Committee (Alberta Teachers' Association, 1997), at arm's length, reviewed the status of special education and made thirty recommendations to assist with the successful inclusion of children. The Alberta School Boards Association struck In the Balance… Meeting Special Needs Within Public Education Task Force (1997). One recommendation was the Government of Alberta provide sufficient funding to support the structures essential to an effective inclusive education system.

The Provincial policies and reports increasingly reflect an awareness that children with developmental disabilities belong in the regular class. However, despite the policy rhetoric of the Government of Alberta (Alberta Education, 1990, 1993, 1997) which supports the inclusion of children and youth into regular classrooms, the placement of children with developmental disabilities into segregated classrooms continues to be the norm (McBeath, 2000; Winzer, 1999).

Nationally

In a national report (1992), prepared by the Roeher Institute for Health and Welfare Canada, the authors point to factors that impede inclusion from happening more widely. They contend,

> (too) often young people are denied access to regular schools because of confused educational policy and lack of leadership. Other problems include improperly conceived and executed funding practices, inadequate support infrastructures, inadequate teacher training, fear, lack of determination to include young people

> with disabilities, lack of knowledge on the part of educators and systemic inertia. (Crawford & Porter, 1992, p. 2)

They argue that we are at a crossroads. "Inclusive education is possible. We can either continue to find reasons for falling short of that goal, or we can choose to move resolutely and do what ultimately must be done" (p. 2).

Internationally

There is a growing international consensus that all children have the right to be educated together in inclusive schools (Armstrong, Armstrong & Barton, 2000; Ballard, 1999; Daniels & Garner, 1999; Slee, 1993). Initiatives from the United Nations, UNESCO, and Non-Governmental Organizations have contributed to this growing international movement. In the past ten years a number of international statements have appeared to strengthen the principles of inclusive education and the importance of working towards schools for all. The United Nations Convention on the Rights of the Child (1989), the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993) and the UNESCO's Salamanca Statement and Framework for Action (1994) are powerful tools that speak to the elimination of segregated classrooms and reinforce the right of children with disabilities to attend inclusive schools. These documents create a strong case for putting inclusive education on the agenda of national governments because the idea of inclusive education is a serious issue concerned with human rights, equal opportunity and social justice. "The extent to which the rights, privileges and responsibilities of citizenship are extended to all members of a society is a topic of increasing national and international importance" (Armstrong, Armstrong & Barton, 2000, p. 1).

Australia

Equity is an established principle in Australia. The Commonwealth legislation, "The Disability Discrimination Act" (DDA) passed in parliament in 1992 and in effect March 1993, supports equitable treatment for persons with disabilities. The objectives of the act are:

a) to eliminate, as far as possible, discrimination against persons on the ground of disability

b) to ensure that people with disabilities have the same rights before the law as the rest of the community

c) to promote the principle that people with disabilities have the same rights as the rest of the community. (Department of Education, Training and Employment, 2000, card 1)

While the DDA legislation is helpful in addressing discrimination towards individuals with disabilities, it has not guaranteed that discrimination in education does not occur, in particular in the area of inclusive education for students with disabilities (Jackson, McAfee & Cockram, 1999). In compliance with the Act, education systems are required to allow individuals with disabilities access to education with the necessary supports and environmental adaptations. However, there are limitations to this broad requirement and school systems across the country are not required to offer students with disabilities access to schooling in a regular classroom. This limitation is

> covered under the 'unjustifiable hardship' provisions which require a balancing of the likely benefit or detriment to the people concerned; consideration of the effect of the disability; the cost of meeting the requirements of the Act; and the

requirements set out in Action Plans given to the HREOC [*Human Rights and Equal Opportunity Commission]*" (Jackson, McAfee & Cockram,1999, p. 4).

The law requires school authorities to provide reasonable adjustments to accommodate for a student with a disability. A reasonable adjustment may include removing a physical barrier, changing a classroom routine or adapting curriculum delivery. An unjustifiable hardship would be if the adjustment required to accommodate a person with a disability imposed an unreasonable burden on the organization. Therefore, it is not unlawful to deny access if a student requires a service or facilities that would be an unjustifiable hardship for the educational authority to provide. Furthermore, the Act under section 45 Special Measures, states it is not unlawful to discriminate if it is the only way to ensure a person with a disability has equal opportunities in relation to education, employment, sport, access to goods and services and capacity to live independently. Therefore it is lawful to provide special segregated classes, special education units and programs as an option for students with disabilities.

Over the past decade in Australia, like Canada, there has been a significant increase of parents requesting inclusive education for their children with disabilities (Connaughton, 1996: Geoghegan, 1996; Lyons, 1993; Robinson, 1996). Legislation and public policy, that makes it unlawful to discriminate on the grounds of a disability, have contributed to this growing trend. To secure inclusion, parents have had to work to negotiate enrolment for their children in local schools and have encountered resistance and sometimes denial of their request. To access inclusive education some parents have had to go as far as making complaints to the Human Relations and Equal Opportunity Commission (HREOC) Tribunal. Complaints to HREOC can take several years to be heard, which is emotionally draining and a financial strain on families. Due to this, many parents drop their complaints and do not pursue inclusive education for their children (Jackson, McAfee & Cockram, 1999). In spite of these barriers there is an increasingly vocal group of parents that are aware of their rights, enshrined in legislature (Epstein-Frisch, 1996). These parents are playing a significant role in promoting the rights of their children with disabilities to have inclusive education experiences.

Access to Inclusive Education

Today, inclusion in the regular classroom in Alberta, Canada and Australia is a reality for some because parents and others have taken strong positions, and taken on the fight – much like the parents of a previous generation. By individual action and success at getting what they wish for their children, parents are laying the groundwork for future change to education policy and law.

There are parents who continue to struggle to gain inclusion for their children. Over the years since Paul gained access to an inclusive education I have seen the struggles parents have to take up again and again. This struggle is one that must be fought again and again by parents. It is stories of mothers' struggles that I seek to tell in this dissertation. Little research explores parental experiences with advocating for inclusive education. In this research I seek to gain an understanding of, and to make meaning of, mothers' narratives of experiences in securing inclusive education for their children with disabilities.

CHAPTER II

METHODOLOGY FOR INQUIRY

Narrative Inquiry

> Humans are storytelling organisms who individually and socially, lead storied lives. (Connelly & Clandinin, 1990, p. 2)

Narrative inquirers are interested in lived experience. We seek to understand the storied lives our participants and we lead on storied landscapes. "Experience is what we study, and we study it narratively because narrative thinking is a key form of experience and a key way of writing and thinking about it" (Clandinin & Connelly, 2000, p. 18). The telling and retelling of stories is "fundamental to human search for meaning" (Bateson, 1989, p. 34). We are concerned with people's lived and told stories. "Stories constitute lived stories, individual and collective, retold and reconstrued" (Ely, Vinz, Downing & Anzul, 1997, p. 64). Narrative inquiry provides a way of understanding and representing these lived experiences.

Narrative inquiry creates an opportunity to engage, explore and enhance human experience and provides the opportunity for research participants to tell their stories in their own terms. Narrative is both a method of inquiry and a way of knowing. As Clandinin and Connelly (1994) have pointed out, they "... use the reasonably well-established device of calling the phenomenon story and the inquiry narrative. Thus we say that people by nature lead storied lives and tell stories of those lives, whereas narrative researchers describe such lives, collect and tell stories of them, and write narratives of experiences" (p. 416). Clandinin and Connelly (2000) propose that if we understand our world narratively, it makes sense to study our world narratively. The purpose of narrative inquiry is to make sense of life as lived.

Clandinin and Connelly (1995) describe contexts using a metaphor of landscapes. Their use of the landscape metaphor gives a "sense of expansiveness and the possibility of being filled with diverse people, things and events in different relationships" (Clandinin & Connelly, 1995, p. 4). Their notion of storied landscapes creates a way of understanding how the context in which we live shapes our experiences and our understandings. "These settings, each understood in terms of personal and social narratives of experience, weave a matrix of storied influence over one another" (Clandinin & Connelly, 1995, p. 27).

As researcher, I enter these storied landscapes and work within a three-dimensional narrative space "…with temporality along one dimension, the personal and the social along a second dimension, and place along a third" (Clandinin & Connelly, 2000, p. 50). The temporal dimension refers to the past, present, and future and allows for a backward and forward motion within the research process. The personal and social dimension has a direction of inward and outward. Inward is concerned with the internal conditions, such as feelings, hopes, aesthetic reactions and moral dispositions. Outward refers to the existential conditions, that is, the environment. The third dimension refers to the places where one is positioned or not positioned. Our storied lives are situated in specific places or sequences of places and, as researchers, we "attend to the specific concrete physical and topological boundaries of inquiry space" (Clandinin & Connelly, 2000, p. 51).

Why Narrative Inquiry?

Upon reading my narrative, a story of advocacy, one may ask the question, why have I selected narrative inquiry for this research? Why not critical theory? Why not grounded theory? Why not emancipatory research? (Lather, 1986). What will narrative inquiry help me to learn about my research puzzle that other theories or methods will not? My inquiry intention was to hear the stories of mothers' experiences of gaining inclusive education for their children. Through hearing their stories, narrative inquiry allowed me to create a research text that illuminated the experiences of mothers. The research was not focused on the development of empowering approaches to generating knowledge. Rather my research concern was to gain an understanding of, and make meaning of, mothers' narratives experiences in securing inclusive education for their children with developmental disabilities. Narrative inquiry was a way to understand the mothers' experiences.

What I Hear in Three-Dimensional Narrative Inquiry Space

As a researcher I see myself as part of a nested set of stories (Clandinin & Connelly, 2000). I understand my location as researcher in the narrative inquiry and tell stories of myself as a teacher and as an advocate for inclusive education. While listening to the mothers' stories I relived my narrative of experiences of advocacy. This research provided the opportunity to tell, retell and relive these stories (Clandinin & Connelly, 1994). The mothers' stories and mine are nested within each other and, through conversations, I gained a sense of how their and my stories were nested together. In listening to the mothers' narratives of advocacy I gained understanding of how my advocacy efforts may have been experienced by Linda and other parents. The narrative inquiry process gave the mothers and myself the space to move back and forward, inward and outward in the exploration of the social considerations of the mothers' advocacy experiences.

Who Am I In The Three-Dimensional Narrative Space?

As a researcher I worked to suppress my need to make meaning of the mothers' experiences as they spoke. For "… the scholar's search for generalizations undermines the interviewer's need to attend to an individual's experience. Ideally, the process of analysis should be suspended to or at least subordinated to the process of listening" (Anderson & Jack, 1991, p. 15). I guarded against what I already thought I knew about what the mothers would say because I would no longer be listening to their stories but rather listening to what they said that would fit into what I thought I already knew. I worked to listen and not allow my assumptions to prevent me from understanding the significance of what the mothers were saying (Yow, 1994). I worked against being predisposed to look for an outcome that paralleled my narrative of experience (Lather, 1986).

I remained awake to this concern as I engaged in the conversations with my participants. As Oakley (1981) from her own research experience asserts, traditional interview method creates problems for researchers whose primary goal is to validate the participants' experiences. A more dialogic approach, that is interactive with the researcher engaging in self-disclosure, creates a more collaborative mutually understood research experience for the researcher and participants. In the interactive conversational space I remained attentive to the participants' sharing of experiences and ensured my reflections upon my experiences were in response to the mothers' experiences. In this way I tried to ensure I did not shape the direction of the conversations to my ways of knowing and away from theirs. Because I am positioned differently on the landscape, my experiences are not the same as the mothers' experiences. It is their experience with advocacy for their children I sought to understand.

CONDUCTING THE NARRATIVE INQUIRY

In my dissertation, I seek to show my research journey. I open with the composition of my narrative beginnings as an advocate and teacher as the first phase of my inquiry. This telling gives sense to the idea of working "within the three-dimensional space, telling stories of our past that frame our present standpoint, moving back and forth from the personal to the social, and situating it all in place" (Clandinin & Connelly, 2000, p. 70). Writing this narrative as the starting place acts to locate me in the stories I was living and telling as I began my research inquiry. It helped me to find my place in the inquiry plotline.

In the second phase of the narrative inquiry, I explored, with two mothers, their advocacy efforts to secure inclusive education for their children. In this phase of the research, I created a place for the voices of mothers to be heard so as to understand their experiences in securing inclusive education. The mothers participated in a series of extensive conversations. The number of meetings were determined and negotiated with the research participants as we worked together to "unlock deeper levels of the data content" (Lather, 1986, p. 264) of each conversation. For participant one we had six conversations and for the other participant we had three conversations.

Within these conversations, I explored with the mothers their efforts and actions to secure inclusive education for their children. I encouraged the mothers to explain, in depth, the complex web of feelings and range of emotions surrounding their experiences.

I wanted to know how and what the mothers felt about their efforts to get their children included in addition to the process they went through to accomplish this. I encouraged them to talk about their feelings as well as their dealings with securing inclusion as they moved inward, outward, forward and backwards upon their storied landscape of advocacy.

In the third phase of this research, I invited four parents, whose children are included in their neighbourhood schools, to participate in two group conversations where the mothers' stories (written as poetic transcriptions), from phase two, were shared. Prior to the conversations, the parents were given a copy of the two stories. They were asked to reflect on the mothers' narrative accounts and to make meaning of these accounts in relation to their own past, present and possible future advocacy efforts for their children. When I first constructed this phase of the research I was uncertain about what this phase would bring to my understanding of parents' advocacy efforts. I wondered what happens when we share stories and are open to where they may lead us.

Initially, I set out to understand how the stories of the two mothers in phase two would inform other parents. I conceptualized that the sharing of the two mothers' narratives would help other parents understand the critical components of strategies to assist them in advocating for their children. However, although the parents in the third phase may have been informed about advocacy strategies, it was listening to the parents' responses to the narratives that helped me realize they were serving a different purpose from what I anticipated. These four parents became involved in interpreting and co-constructing meaning of the two research participants' narratives of experience. Their insights were a valued component in my research inquiry. The parents acted in ways similar to what is termed in research as "critical friends" (Costa & Kallick, 1993; Stoll, 1998; Zimmerman & Lee, 1998). "A critical friend, as the name suggests, is a trusted person who asks provocative questions, provides data to be examined through another lens, and offers critique of a person's work as a friend" (Costa & Kallick, 1993, p. 50). The four parents responded to the narratives of experience and provided another lens to view the two mothers' experiences. They nudged me to see the experiences from another perspective.

Critical friends in the research process are usually other researchers. However, in my inquiry I opened the role of critical friends to parents when I asked the group to reflect on the meaning of the mothers' narrative accounts. In researching mothers' narratives, it seemed appropriate to have parents, in similar situations, act as critical friends to respond to my work. The second time we met, I shared with the parents how I had viewed them as critical friends and they were pleased with the contribution they had made in supporting the research.

The phases of the research played out within the three-dimensional narrative inquiry space, temporally beginning with my past advocacy efforts, sliding forward to mothers' experiences, then moving to present-day experiences of making meaning of the mothers' experiences. The telling and retelling of my participants' narratives of advocating for inclusive education made space for the participants to share both personal and social dimensions of the experience, while the unfolding narratives contributed to understanding the places where the participants' storied lives are situated.

Selection of Participants

In phase two, two mothers were asked to participate in a series of in-depth conversations. I asked one mother from Alberta and one mother from South Australia to participate. The selection of research participants in two countries provided an opportunity for an international conversation about advocacy efforts to secure inclusive education. The two perspectives brought forward further insight and different strategies parents used in their efforts to secure inclusion for their children. In Alberta, I chose a mother with whom I was in relation, while the selection of the Australian mother was negotiated through the help of a professor at Flinders University, South Australia.

Negotiating a relationship with each research participant required the development of a trust bond. To accomplish this I began by giving each participating mother a copy of my research proposal. My personal narrative provided an offering to my research participants, in the beginning step, of my willingness to open myself to them. The proposal provided, as the first step, an invitation into the research process by giving them an understanding of how I came to desire to research their lived experiences with securing inclusive education for their sons. Oakley (1981) says "(n)o intimacy without reciprocity" (p. 49). Beginning the conversation by sharing my own narrative created an opportunity for the mothers to see who I was in relation to advocacy and inclusive education. The intimacy implied in sharing my efforts was important as I was asking the mothers to share their own intimate experiences with me.

For the phase of critical friends, four parents from Alberta, whose children are presently included in their neighbourhood schools, participated in the research inquiry. I located these parents through my various volunteer activities with families who have children with developmental disabilities.

Phase Two Participant One: Valerie

Unknown to me, Valerie knew me before I met her. She heard me speak at a conference eight years before we met personally. Our formal meeting was facilitated through my husband Paul, who worked at Alberta Association for Community Living (an advocacy organization) as a Community Development Advocate. At the time, he was assisting Valerie with a placement appeal with her school board. During the dispute Valerie's son, Jason, stayed home for a year. My husband asked me, as a teacher, to help Valerie and a program assistant, hired to work with Jason at home, to develop an appropriate education program for him. In the fall of 1997 I met Valerie at her home, situated an hour drive from a large urban centre. Throughout the year I made this trip numerous times to support the program assistant in her home instruction with Jason. Valerie's and my relationship continued to grow after our first formal meeting.

In getting to know Valerie, I learned she had two sons, one with a disability and one without a disability. Her husband has his own business in their community. Valerie is active in her church community and is a faithful follower of her religion. Her religious beliefs are central in her way of knowing. In addition to being active in her church, Valerie sat on government committees representing parents with children with developmental disabilities. She continually advocates for her son's inclusion in all aspects of community life.

In the spring of 2000, prior to defending my research proposal, Valerie agreed to participate in the research. In May 2000, Valerie participated in the first of six conversations that took place over the next four months at her home. Each conversation ranged from one and one half hours to two hours long. On the basis of our conversations, a poetic transcription and narrative account of Valerie's experiences with securing inclusion for her son was written. These interpretations were shared with Valerie and further discussions shaped the final presentation of Valerie's telling of her lived story advocating for her son.

Phase Two Participant Two: Sandi

Securing Sandi as a research participant was negotiated through a colleague, a professor at Flinders University, South Australia. In the fall of 1999 I wrote to my colleague asking her assistance in locating a parent willing to be a research participant. My introduction to Sandi was through e-mail. Sandi's response to being a research participant was enthusiastic from the start. When I arrived in South Australia Sandi welcomed me into her life. Between taped conversations Sandi took me to meetings, on school tours, and to her home to meet her family.

In the time I spent with Sandi, over a period of four weeks, I learned she is a single parent with three boys, Aaron, age 14, Cameron, age 10 and Jacob, age 9. During my visit Jacob had his ninth birthday and I was invited to the celebration. This was one of many invitations to spend time with Sandi's family. The time with her family was fun and entertaining as the three boys shared their lives with me. Our conversations were filled with accounts of their daily activities and accounts of my life in Canada. I saw them as a tightly knit family. Sandi and her three boys were always looking out for each other.

Sandi is passionate about inclusive education and about advocating for the rights of people with disabilities. Cameron, her son, born with a disability, is her driving force.

She sits on both local advocacy group boards and national government committees. She has written articles for advocacy journals and prepared reports for research on the status of inclusive education in Australia. She is a tireless advocate and uses every opportunity to bring to consciousness the need to change the discrimination she witnesses towards people with disabilities.

On October 31, 2000, Sandi participated in the first of three conversations that took place over four weeks. Conversations with Sandi ranged from two hours to three hours long. Using transcripts of our conversations, a poetic transcription and narrative account of Sandi's experience securing inclusion for her son was written. These interpretations were shared with Sandi via e-mail, and further discussions via e-mail contributed to the final representation of Sandi's narrative of experiences of advocating for Cameron.

Constructing Field Texts

Conversations between the participants and myself formed the basis of data collection. The conversations were interactive in nature. Oakley (1981) suggests that in an interactive conversation the researcher is more than an instrument for data collection. Rather, both the researcher and the participant are considered sources of information. Therefore, we both shared information and contributed to the research process. The conversations were the sharing of ideas, philosophy and experiences. The conversations were a sharing of ourselves. After each conversation I transcribed the taped conversation. Before I met with Valerie for our next conversation, I mailed her a copy of the interview. Due to time constraints, I delivered a transcribed copy of our previous conversation to Sandi at the next scheduled meeting.

Intensive conversations as a methodology provided me the opportunity to discover information about the participants' experiences in their words. Rather than have a set of predetermined questions to guide our conversations, I relied on questions that arose from the conversations to further explore the participants' experiences. This created a space for the participants to shape the conversations.

In addition to the taped conversations with participants, my stories, personal journals and other documents (government documents, media stories, correspondence, etc.) were also used to contextualize the research work.

From Field Texts to Research Texts: Narrative Analysis

I began the interpretation by transcribing the tapes from our conversations so that I could read the transcripts to locate conversational threads. I read each participant's narrative from beginning to end. I re-read the transcripts looking for linking elements in the discourse. I arranged and sequenced ideas or trains of thoughts together by cutting and pasting them under general headings. Reading these newly arranged transcripts I looked for emerging themes within each participant's story. I then reflected on the emerging themes within each participant's story and wrote a narrative account of the dominant themes noted within both their stories.

In addition to the analytical description I prepared poetic transcriptions (Glesne, 1997) of the participants' narratives. I did this through the process of reading through the original transcripts and highlighting phrases that illustrated the participants' narrative account of advocating for their sons. Then I arranged the highlighted phrases in a chronological order to re-present the participants' experiences.

The participants were given copies of the analytical description and poetic transcriptions. I mailed them to Valerie and e-mailed copies to Sandi. I asked them to respond to the accuracy of the re-presentation of their narratives. I encouraged them to state if the narrative account and poetic transcriptions re-presented their own interpretation of their situations. When they asked for changes, we negotiated how the document would be changed to reflect their interpretation of the situation.

Constructing the Research Text

In re-presenting Valerie and Sandi's stories I felt a need to remain in relation with them in some manner. In the following section is a letter written to my participants explaining my attempt to create a more relational form. Valerie and Sandi's experiences were connected with each other in terms of similarities while other aspects of their experiences were indicative of differences. I wanted to re-present this while remaining connected to them individually and collectively as I re-presented their narratives of experiences.

What follows is one of many letters written to my research participants, which forms a portion of the written re-presentation of my work with my participants.

Dear Valerie and Sandi,

In presenting your narrative accounts, I wanted to link your stories with each other as I stayed in relation with you. As I grappled with this idea I sought to discover how other researchers wrote narrative accounts of their participants' stories while remaining connected with them. Mickelson (2000), in her book titled ***"Our sons were labelled behaviour disordered: Here are the stories of our lives,"*** also struggled with the established traditions of research and its predetermined ways of writing research results. In her search for alternative ways of representation she discovered a growing body of research that supported writing narrative research in a variety of creative forms. Mickelson chose to write collective letters to the mothers in her research linking their stories and weaving theory through her narrative accounts. She chose this approach for she wished to make connections between her words and the participants' experiences rather than writing each into separate chapters. Mickelson, representing her research in the form of letters, brings forward the relational nature of her research work with the four mothers while noting the similarities and differences in her research participants' experiences.

As I entered the writing phase of my research I thought about the time we spent together in the data collection phase. As I read and re-read your transcripts I could hear your voices. Images of where we each sat when we met flashed through my mind: Sandi, I heard the wind blowing, the birds chirping in your back yard, Valerie, the sound of construction as your street was being torn up. These occasions were filled with intense conversations where I felt we developed a strong sense of mutual support and connection to each other. Through our narrative inquiry we created and cultivated a relationship that had the characteristics of openness and trust. It was this feeling I wanted to represent as I began to write your narratives. Shared letters seemed a way to maintain this feeling of connection that we had begun to form in the time we spent together. This is why I chose to write our stories, yours and mine, as letters to you, both collectively and individually linking your stories of similarities and differences with my reflections as I heard your words and theory that related to your experiences.

As Mickelson did with her co-researchers, I am retelling your stories. I may have passed over aspects shared with me that you think are crucial to an understanding of your experiences, or I may be including things you do not wish to be read. If this is so, please let me know so we can discuss these exclusions or inclusions and agree upon changes. You are the author of your story while I am the author of this narrative of your story. It is important that this narrative account represents your interpretation of your story. Some of my understandings may not fit for you and I am confident you will let me know if this happens.

With Warm Regard,

Heather

Ethical Considerations

All participants in this research, including those with whom I had individual and group conversations, signed an agreement indicating their willingness to participate (see Appendix). They were informed of their right to withdraw from the research at any point in the research process. Anonymity was promised but participants were also offered the opportunity to author their own parts in the study using their own names. If they chose anonymity they were guaranteed that their responses would be treated with confidentiality and pseudonyms would be used. One parent in phase two wished to use her first name while the other chose a pseudonym. Valerie and Jason are pseudonyms and Sandi and Cameron are the other participants' real names.

Participants were given the opportunity to read draft sections of the dissertation, with the intention of developing a collaborative interpretation of their 'story.' This sharing of the research text assisted in ascertaining the verisimilitude of the text (Connelly & Clandinin, 1990). Since the parents voluntarily provided all the field text in the research, the experiences shared posed no significant ethical risk to them.

CHAPTER III

NARRATIVE POEMS

Dear Valerie and Sandi,

I am sending, what I call poetic transcriptions (Glesne, 1997) of your narratives. I chose to re-present your words in this way, so as to give our work an aesthetic sense. Presenting your words in a poetic transcription, before unravelling them in an analytical description, creates the space for the inclusion of the emotional component of our work together. I did not initially plan to write poetic transcriptions of our interviews. However, when I worked with our typed transcripts, I decided your narratives could be best presented through creating poetry from your words. Conversations with fellow research colleagues at university the previous months had been focused on exploring different ways of representation research (Butler-Kisber, 1998; Ely, M., Vinz R., Downing, M. & Enzul, M., 1997). With these conversations in my mind, as I read your words, the poetic impulse took over and I created poetic transcriptions of your narrative accounts as parent advocates.

The words in the poetic transcription are your words. However, I created the poetic transcription by pulling words and phrases from the transcripts of our conversations. I placed your words together in a chronological manner to illustrate your narrative of advocating for your sons' inclusion in school. I attempted to keep enough of your words together to re-present the way you spoke. I gave myself permission to add or drop endings (e.g., ing, s, ly) and to occasionally change verb tense. "Poetic transcription is also filtered through the researcher but involves word reduction while illuminating the wholeness and interconnections of thoughts" (Glesne, 1997, p. 204). Although they are your words, I have staged the script in the way they were placed on the page. I took your stories and placed them in what I hope reflects a chronological re-presentation of your lives as you advocated for your sons. My intent in creating poetic transcriptions was to have the reader come to know both your narratives of securing inclusion for your sons in as few words as possible and in that way provide a portrait of your lives as parent advocates. Using your words I hoped that I have composed a story that makes a point or evokes a feeling told, heard and felt by others as they get to know both of you.

VALERIE[2]

Before Jason[3]

It goes back,
Before having Jason
Delbert was his name.
He didn't have much speech.
He had a special name for me,
Hawkeye.[4]
He saw that in me,
Something I didn't see in myself.

That is a big part of me,
Seeing past the differences.
What makes them apart?
Different from the rest?
Friends who didn't fit the mold,
They were good friendships.

Jason came along,
Okay, we'll deal with this,
It wasn't so terribly hard.

I never imagined,
The strength, courage, energy and work,
It would take,
Dealing with the world,

---

[2] Pseudonyms are used for all participants unless otherwise stated.
[3] Jason is Valerie's son who has been labelled autistic.
[4] I looked in Webster's dictionary for a definition for the word Hawkeye and it said "keen sighted."

Not Jason.

Why Inclusion?

Why was it so,
The decision for inclusion?
Why inclusion?
Conference?
Speaker Heather?
Kevin's story.
It may have been in my subconscious.
I don't know.

I'm convinced,
God given,
God's wisdom,
Knowing what was right.
Learning to rely on God for,
Direction,
Wisdom,
Insight,
Strength,
Courage, and,
Energy.

Daycare?

He was vulnerable, tiny and three.
I didn't want to do this.
He needed to be with other kids.
Play school an option but,
He needed five days a week.
He needed kids every day.
I was nervous,
Other people taking care of him,
Knowing it was good for him,
Not really trusting them.
One day,
Walking in,
Jason sitting by himself,
Aide's supposed to be with him.
She wasn't anywhere to be seen.
Hit the roof,
My baby's in your care,
What's going on here?

Blasted them.
Walking out.
Started thinking,
Was she in the washroom?
Yes, oh no,
But they had to realize,
What they were dealing with,
It was hard for me.

Director

Telling her,
I want to know,
From the time he arrives.
I need to know why he's here.
I want to know how you help him grow.
Even if for this time you are in charge,
It is still my responsibility.
I am not going to let you,
Take complete responsibility of him.

Meeting

It's about Jason,
This meeting is about my son.
What are you saying about him?
How you are teaching him.
How I am teaching him at home.
We need to generalize.
I'm attending.
Stunned, big eyes, mouths opened!
I waited.
They struggled.
No parent before expected this.
Shocked and stunned.
What do you mean,
No parent wants to know?
Maybe they did not have the courage or they did not care.
They slowly accepted me,
They didn't have a choice.
It didn't bother me,
They didn't want me there.
They didn't make me feel uncomfortable,
At that stage I don't know if I would have cared.
I wasn't going to be uncomfortable,

They could do whatever they wanted.
I was in charge.
I wouldn't let them rule his life.
It was stressful.
But because of the high energy,
It didn't affect me.
I was just this powerhouse,
That knew there is no way I could,
Possibly face the hurdles without God.
Staying right on track without ever doubting,
God is why I've been able to stay so strong.

Daycare Program Unit Grant

Sharon[5]?
Who is this woman?
I didn't have a clue.
Why was she here?
She's from the school.
She okays the grants.
She had these great ideas.
I expected her to explain,
In a way that I understood.
That was difficult for her.
Parents never question.
I am so grateful I could.
The Lord gave me this personality,
I can just go in and question.
I am so grateful I had the courage.
God given,
The wisdom to know.
To not get caught up in pitying Jason,
But rather holding strong.
First seek the counsel of the Lord.[6]
That give me incredible inner strength,
In spite of panic attacks and those kinds of things.

Battle for Swimming

I wanted a swim program.
Sharon wasn't going to give it to Jason.

---

[5] Sharon is a senior school staff that oversaw special education for her district.

[6] This quote from the bible, is one of a number, Valerie read during a conversation. They represent to her how the Lord's words guided her during her struggles for Jason's inclusion in the community and his neighbourhood school. All biblical quotes are italicized.

She admits money's not the issue.
I wasn't going to accept this.
You're not going to deprive him.
It was just a control thing.
She wanted to be able to say yes or no.
I was pushy,
Personality clashes,
She's the professional,
Nobody questions her.

Phoned consultants for support.
Sharon says, "The parents want a swim program,
I'm not convinced it's necessary."
She looks to the consultants,
They say, "It is essential."
"Beneficial you mean, not essential," says Sharon.
"Critical," they say.
What could Sharon say?
"I will authorize the swim program,
But will not authorize the aide."
I was bawling,
Why shouldn't she be there?
Sharon says, "We will have to meet to discuss it."
I left,
Phoned her office,
Set a date,
Came back,
Told Sharon,
"I am meeting with you at two tomorrow."
Sat down,
Gutsy me,
Blows me away.

Kindergarten

Went to Sharon,
Want to know the spectrum.

She gave me the whole gamut,
It's a pyramid thing? [7]

She planned to send him across town,
To the special education program.
She was putting pressure on me,
When he was only five.

Principal

Golfed with Kevin[8],
I sort of knew him.
I was comfortable going to him.
Jason needs to go to this school,
He has autism,
He needs support,
He needs to be in his neighbourhood.
He looked at me,
I had no idea what reaction it was going to be.
He said,
"When Jason's ready for us,
We'll be ready for him."

Transition

Kindergarten's coming,
Must deal with Sharon.
She's on sabbatical,
Relieved she was gone.
The brick wall was out of there.
Talked to this guy Sam[9],
He was filling in for her.
Told him the stories.
"You're going to tell me,
It's too early to make a decision."
It was January.

---

[7] From the conversation I realized Valerie was referring to the Cascade Model. This model has been the accepted conceptualization of service delivery for children with special needs throughout North America since the 60s. In Canada, the cascade model has been used as an administrative model for delivering special education services. In order to serve children of varying levels of disability, the cascade model proposes that a continuum of placement options be available. The continuum of placements and services is depicted as an inverted pyramid which contains eleven administrative plans in special education for students with disabilities, ranging from fully integrated to fully segregated settings and from a higher student/teacher ratio to a lower student/teacher ratio.

[8] Kevin is Valerie's husband.

[9] Sam took Sharon's responsibilities while she was on sabbatical.

The principal says he's ready.
Sam grabbed a memo,
Scribbled out a note,
Jason's going to his neighbourhood school.
God given gift Sam was.

Elementary

Jason went to Kindergarten,
Elementary was fine,
I trusted them.
Hiring new aide.
Prayed about it,
Left it with the Lord,
I am going to trust You.
They hired this gal,
Within days Jason was doing things,
That I knew he could always do.
The Lord gave Jason someone like his mother,
Who wasn't his mother in school.
Complete trust in aide,
She was a Christian.
That was important to me.
She knew the God side of him.
When I said, "We need to pray",
She knew and didn't look at me,
Thinking I was weird, a fanatic, out to lunch.
Seldom had to advocate for him.
She did it.
She had the energy.
She had the drive.
She saw the potential.
She was incredible.
We were blessed.

Grade by Grade

Grade One

Report card,
Teacher was excited.
She was a great teacher.

Grade Two

She was the first teacher that really saw,
The influence Jason had on the class.
I didn't feel any negativity,
I didn't have any uncomfortable feelings.
It was relaxing,
Not worrying about Jason in her class.

Grade Three

She gave me a potted geranium,
Thanked me for the privilege of teaching my son.
That was incredible.

Grade Four

His Grade 4 teacher came by,
To make connections with him in Grade 3.
Upbeat, positive, supportive teacher.
Went the extra mile.

Grade Five

One of his best teachers.
His first man.
Supportive of Jason.
The Grade 6 teacher had been excited,
That whole year knowing Jason was moving up.
Popping in talking to Jason.
He was excited until,
Just before Christmas.
Aide was going,
She was being transferred.
Then fears overwhelmed him.

Grade Six

Needed to hire a new aide.
If present aide involved in interview,
I didn't need to be there.
Trusted her.
Principal interviewed,
Offered the job.
Aide wasn't there,
Betrayed.

Worried for Jason.
End of September,
Warning bells clanging.
Things not going well.
She had no common sense,
Where kids were involved.
It was so obvious but not to anyone else.
They could not see the damage she was doing to him.
I was bewildered, frustrated, angry, devastated.
Trying not to be judgmental,
Not to compare her to the previous aide.
I didn't want to criticize,
I didn't want to interfere.
Things got worse.
I questioned.
A wall went up.
I started seeing a pattern,
How she was setting him up to fail.
Telling him he couldn't do stuff,
She was making him a burden,
An unwanted load.

Jason was coping in incredible ways,
Looking back I see he was.
October started wetting his pants.
Let it go to December.
I couldn't understand,
It was not him.
It happened a couple of times at home,
Realized when he was thinking about his school day.
He was so depressed,
Hurting so much inside.
What drove him to that level?
It was breaking my heart.

Over Christmas it stopped.
Then he started getting mad,
He got madder and madder and madder and madder.
Something in him retaliated,
It was like he just became angrier and angrier and angrier and angrier.
He screamed at the top of his lungs,
Blood curdling screams.
I didn't condone the screaming,
But I was glad he was mad,
He cared about the world and himself.

I was so glad to see that anger,
I would rather see that than see him withdraw.
It is better that he had the courage to stand up to her,
Yelling at her,
Not letting her control him.

Grade Seven

Sharon said, "Special education!"
Had nothing to do with Jason,
Had everything to do with control.
The board supported her,
At an unquestionable level.

Help On The Horizon

The Lord did it.
Shirley[10] phoned me,
She worked at the school.
Heard through the grape vine,
Jason was coming.
I don't want to damper you,
But you need to take care,
If he goes into that classroom,
He won't get out of there.
The vibes had started to get through to me,
They had plans for him,
Special education.

Shirley phoned again.
Said there were other parents,
Told me about this Paul[11],
Would I be interested in a meeting?
I was too stressed to go,
I said, "Yeah" and never had another thought,
No intention of going.
She phoned again,
Said she needed a meeting place.
She was staff,
Parents couldn't meet at her house,

---

[10] Shirley works in the school district as a program aide and also has a child with a developmental disability whom she wanted to attend his neighbourhood school in an integrated class.

[11] Paul (real name) is a Community Advocate who worked for the Alberta Association for Community Living which is a non-profit association that advocates on behalf of families and individuals with developmental disabilities.

Because it was AACL[12].
I didn't understand the political stuff.
She said, " Would you mind?"
I didn't really want to but said, "Okay."
I had it at my house,
Paul comes briefcase full of things.
Everyone shares,
I share my letter to the Board.
Paul says it's too long.
I couldn't change it,
It said everything that was important.

Paul called many times,
"How are things going?"
I would say, "One more meeting,
I think they will hear me."
Paul would say,
"That's not the norm,
That is not what has happened in the past.
I don't expect that to happen,
But I hope you are right."
He didn't push,
Letting me play it out for myself.

Be strong and courageous
Do not be afraid or discouraged.

Moments of hopelessness,
Hopeless feelings came.
I went straight to the Lord.
I knew that He knows how this is working.
I see no possible way to go,
I see a brick wall.
There is no other way.
Knowing that He is more powerful,
He had a way.
He gave me hope.
Gave direction.

Round Two

Sharon phoned,
"I need you to come at 11:30 today.

---

[12] AACL stands for the Alberta Association for Community Living.

You are not going to like the things I have to say."
I should have said, "No!
I can't come today,
We will need to schedule it another day."
I said, "Fine."
Phoned half a dozen friends,
Start praying,
I don't know what is going on.
I went.
She said, "Jason's friends would be too stressed,
To have a friend like him in junior high."
I told her, "You don't have any idea,
What my son's relations are with his friends,
You don't have a clue."
She sat there.
She insulted him.
I told her, " I don't trust you."
This woman never loses control.
She's got this stone face.
She lost it,
She slapped the desk jumping up,
Leaned over and said,
"How dare you say you don't trust me."
I looked at her and said,
"Do you really want to get into this?
It goes back to day care days.
You had no reason whatsoever,
Not to give him swim lessons.
You just didn't want to do it.
You want me to trust you?
You're not trustworthy."
She sat down with a thump,
Realizing she had lost it.
She was shocked,
She had lost control.

It was incredible,
I didn't fly across the desk,
And start choking her.
She insulted my son.
I didn't lose it,
The Lord kept me in my chair,
And kept my voice calm.
I confronted everything she said.

How could I tell a 13-year-old boy,
Going into adolescence,
He worked so hard all these years,
To be in the world,
Be successful there and,
Be welcomed there,
It didn't matter because he was still too different.
I told her,
"I wouldn't let you take him away from his friends,
Or take his friends away from him."

There is the miracle,
That meeting shows,
That God was with me.
I calmly said those things,
I wasn't ranting,
I wasn't swearing.
I just said them,
With conviction.
She realized then,
She had a fight on her hands.
Yet she still had such incredible confidence,
In her own control of things.
I wasn't going to interfere,
With her plan for Jason.
No one was going to tell her,
Her expertise,
Her experience,
Her incredible position of control.
She expected that her plan would happen.
I didn't feel like I had won,
But looking back,
I'd won this round.

I left wondering,
"Okay God where were You?
I need Your help here,
Where are You?"
I knew what was right.
I just didn't know how to defend it.
I didn't know how to make them see it.
I thought they would see it,
But they didn't.
I was betrayed and heart broken.
They could not see Jason,

They did not value him.
Although he proved he could be included for years,
All of a sudden it wasn't enough.
I couldn't understand.
How could I tell him that it wasn't enough?
How can you see this build and succeed,
And be positive for him and his classmates?
How can they see that and still not,
Allow him to continue to grow and be valuable in society?
Instead they just shoved him off,
Cost too much,
Too much work to educate their staff,
So they thought.

Be strong and courageous,
And do the work.
Do not be afraid or discouraged,
For the Lord God is with you,
And He will not fail you,
Or forsake you until all the work,
For the service of the temple of the Lord,
Is finished.

Accepting Help

The miracle of Paul coming into my life.
I didn't want that meeting at my house,
I didn't know the impact,
He would have on our lives.
It was wonderful that he was calling,
I acknowledged and appreciated,
The support he wanted to give,
I didn't think I needed it.
I faxed everything up to him.
He phoned and said,
"You need a lawyer."
AACL would support us,
Help us financially.
If we hadn't had that support,
We could never have done it.
That was the first time,
I had the supports that I needed.
Otherwise Jason would have had to go to a separate class.
It was a relief to not have to do it myself.

It took experts like Susan[13] and Paul,
To see us through it all.
All my emotions,
And my passion.
To get to the simplicity of it all.
There were people in my life,
That knew about the school system,
They knew about the legal stuff,
And how it worked.
It was Greek to me.

AACL anticipating the expense,
They needed to make sure that it was going to go,
It was going to be worth the fight,
That was kind of scary.
I tried not to think about it too much.
I tried to put my trust in Susan and Paul.
To convince this person that it was legit,
AACL agreed.
To me it was people,
Susan and Paul as opposed to AACL,
People supporting us.

I just knew what was right.
But that is not going to get you anywhere.
They just don't hear you.
It was relief to have that support,
At the same time it was frightening.
I was letting go,
I was letting other people,
Control the outcome of Jason's life.
I had to trust them,
There wasn't ever any doubt about that,
But it was scary too.
You are kind of swept into it.
Things happen that you can't control,
Snowballing, becoming this huge thing.

Appeal

In the bible when it said,
David was going out to battle,
He asked God what to do?

---

[13] Susan is a lawyer that was contracted to assist Valerie with her appeal with the school board.

Just like I had done,
Here it says,

As soon as you hear the sounds,
Of marching in the tops of the balsam trees,
Move quickly because that will mean,
The Lord has gone out in front of you.

Be strong,
And let us fight bravely,
For our people.

This was about war.
I took this literally as my fight.
It was those kinds of things,
Be strong,
Don't be afraid.
When I was going through this,
There were a lot of things I underlined[14].
I am not sure why I did it at the time,
Now I see,
It was part of that whole plan,
The big thing.

We would appeal the placement decision.
Given the choices I'd made in raising Jason,
I'd had no choice but to face this difficulty,
There was no other way.
Ensuring Jason grew up confident,
Experiencing all of life any other child does.
The world being confident in Jason as a natural part,
That is what it's all about.

Phoned to say we'll send a letter,
Requested letter to confirm their rejection.
Sharon says the Board's meeting for wind-down BBQ.
I will set the appeal meeting tonight before trustees head off.
Okay, get back to me.
My lawyer involved.
Appeal date July 4th,
Two working days to get ready,
Susan sends a letter,
We won't be there.

---

[14] While Valerie was going through the court cases she read her bible faithfully and underlined many quotes that gave her strength throughout her struggle.

Throughout that summer,
Just waiting.
Nothing was happening,
I was hoping something would,
I guess that was always the hope,
It would happen quickly.
Between Grades 6 and 7,
The uncertainties,
We lived with it the whole summer.

New appeal date August 26th.
They require two weeks to review,
What we were presenting at the appeal.
They didn't give us the option to review,
What they were presenting.
It was so unfair.
We cancelled the next one.
We agreed to meet with Sam[15],
I was just so thrilled.
I thought that it was going to be fine.
Paul came with me.
Sharon gave her perspective,
I gave him mine.
Sam asked me about the hostility,
That Jason would encounter at school.
I felt he betrayed me completely,
By siding with Sharon.
In hindsight I see with Sharon in control,
There would be hostility.
Sharon would not support the school.
Jason would have been a burden in their class,
He would have been unwanted,
Just a hassle,
Too much energy.
The school would get no support,
That was not part of her program.
She probably told Sam straight,
It was not going to happen.
That is probably what he based his decision on,
He was protecting Jason.
I was mad, angry, hurt, frustrated by his decision.
Now I see how right it was,

---

[15] Sam was acting superintendent at the time Jason was moving between Grades 6 and 7.

It was what was best at that time for Jason.
With no support,
Jason would have proven Sharon right.
The way it happened,
Everything has proven us right.
I just have to thank God.

It was when it first happened,
I remember taking a step back,
Saying, "Okay Lord,
Maybe a separate class,
Was best for Jason.
Maybe that's what he needs,
Even if I don't see it.
I need to know Your best for him,
I know Your best,
Is better than I can ever imagine.
Better than I can ever achieve for him.
I need to know what is best for him."
That is when He gave me,
The realization,
That the vision of inclusion,
Was from Him way back.
Even though I didn't know it.
Even though I had thought it was my own,
It was from Him.
He doesn't change things mid-stream,
He doesn't do that.
He moves you along in one direction,
For you to achieve what He wants you to achieve,
He doesn't all of a sudden go backwards,
Switching directions.

Seeking Support

They were helped in fighting them.
Everyone will be ready,
For all the work on the temple of God, and,
Every willing man skilled in any craft,
Will help you in all the work.

I knew,
Every person that needed to be in place,
To finish the work in Jason's life,
To finish God's purpose for his life,

Would be there.
No matter how little,
No matter what kind of little craft,
Whatever we needed.

I phoned,
Could they write a letter to support Jason?
She didn't even return my call.
She wasn't going to support me.
Didn't see the rightness for Jason,
Refused to support Jason.
People that were supposed to be good friends,
I thought they would know better.
Your true colours are showing,
You really weren't a good friend.
Lots of them that did not.
Hard to forgive close friends,
That didn't support him.
That really hurt.

I phoned other friends,
Letters of support.
Jason's friends and their parents,
His classmates wrote and their parents too.
They understood the rightness for Jason.

Let us hold unswervingly,
To hope we profess,
For He who promised is faithful.

First Day of School

Going to register at school tomorrow,
Kevin are you coming?
Why do I have to be there?
If you have to ask you don't get it.
Two dads are going to be there,
How is that going to make you look,
When Jason's friends' dads are there and not his dad?
He decided to go.

CBC.
Nicki's family.
Tommy's family.
Richard's family.

It was hard on this principal,
He doesn't like his feathers ruffled.
CBC in his face,
Jason's friends and their parents too.
Cluster standing in his doorway.
He had to walk through it.
He wanted Kevin and me in his office.
He said, "What are you doing to me?"
"What are we doing to you?
What are you doing to our son?
It is our son that this is all about, not you."
"You know this isn't my issue,
You have to deal with head office."
"If you took a stand this could happen in your school."
"No, you have to deal with head office."
Major media crush,
Nightly News,
CBC,
CFRN,
A-Channel,
The Journal.

Overpowering need to free oneself of stress,
Anxiety, attitudes, struggle, work.
Much easier to bring Jason home,
Shut the door,
Protect ourselves.
That's not the answer.
Wouldn't that be giving up?
People for sure would feel justified in their pity.
This child is too much,
A burden for the mother,
Totally unacceptable.
That is not what Jason is to me.
Never has been.
I could not give up,
Giving the world a perception of Jason, his mom and family,
That was not true.

Continually Seeking Support

Psychologist and speech pathologist,
Assessed him,
Came out supporting him.

All the publicity,
The talk shows,
I was empowered.

There was an older lady from church.
Quiet and meek,
She has got to be 85.
Said to me,
"I heard you on the radio,
I am so proud of you!"
I never forgot that,
She was proud of how I handled that.

The letters to the editors,
So hurtful,
They don't know us.
They have no idea who I am,
Who Jason is and his abilities.

I felt like I was under a microscope,
Being examined by everyone.
They weren't seeing the whole picture,
Just the parts they wanted to see.
There were tons of people,
Who didn't even know I existed,
Weren't aware of Jason's situation.
But I felt everyone knew,
Like a dark unshakable cloud overhead,
Following you everywhere.

The hardest was the church,
Because of my stand with God.
They didn't understand,
It was God directed.
They did not want to believe it.
I could never do it without knowing,
That it was the right thing.
I tried so hard to convince them,
It was God directed,
I just knew that this needed to happen this way.
God given.
God driven.
I knew it was right.
A lot of them said, "I do not understand,
But will pray for God's will."

Good, if you pray for God's will,
I know what that is.
There is more power more people praying,
The more power the faster it will be.
I don't need to try and pound it into their heads.
I don't need to do that.
It was almost surreal.
I was watching them watching me crying, dumping my heart.
They sat there stone-faced.
I thought, "I don't need this,
I don't need to convince you,"
As long as they're praying for God's will.

Grade 6 teacher was willing to write a letter,
As a teacher saying what supports he needed,
For Jason to be successful in his class.
That is what I asked him to do.
Then he said, "I couldn't support Jason,"
Because of his job.
I felt betrayed by that.
Paul helped me to get over that.
I wasn't angry I was just hurt.
Because he had said yes when I had asked him,
Then he wouldn't.

A woman phoned,
She heard me on the radio.
They cross-examined her.
Signed an affidavit,
The same thing happened to her.
They were shipping her son to another town,
A 6-year-old boy,
Transferring from a bus to a taxi at the high school.

The parent from the hockey arena,
He didn't know about education.
But he knew about community stuff,
Important for Jason to be part of the community.
Supporting my point of view,
To the point of sacrificing himself.
That meant a lot to me.
Stepping forward,
Sharing how he saw Jason grow.
How worthy it was for Jason to be out there,
Valuable for him to be there.

He doubted once,
We changed his perspective.
Insisted Jason be at the arena,
Rather than leave him at home.
Now he saw the results ten years later,
It made it all worthwhile.

This new youth pastor and his wife were there.
Krista, this little tiny pastor's wife.
Came up to me and said,
"I think what you are doing is wonderful.
I'm behind you.
If you need anything,
Any help with Jason, I'm there."

Don't be afraid.
Those who are with us,
Are more than those,
Who are with them.

Home Support

Paul started talking about tutoring[16].
An incredible blessing,
New youth Pastor's wife Krista.
Four or five hours a day,
Lord brought them to us,
It was quite wonderful.
Nervous about him doing Grade 7 stuff,
Might make him mad,
He couldn't do it.
He started to do it all on his own.
It was amazing, so awesome.
Would never have known Jason could,
Without the belief he should try.

Round Three

It was out of my hands,
It had a life of its own.
It was scary,
Becoming this huge monster.
Nothing we could do to stop it.

---

[16] Because the Junior High refused to register Jason into the regular Grade 7 class Valerie kept him home.

It was going forward,
It was disturbing me.

I knew in my heart.
My heart was talking,
Not the legal stuff,
Not what the judge needs to hear.
I knew what was right,
I knew what was best,
But that wasn't something they would hear.

I prayed it would be simple,
That it wouldn't get tangled up,
And lost in all this complexity.
I was so caught up in my fears,
I didn't know what that simple truth,
Would boil down to be.
I was so afraid,
The simple truth would,
Get lost in the commotion.
Susan said, "It is simple."
She had just answered my prayer,
And I believe God has shown us the way.
It is how they decided to send him away,
They put him in a slot,
Without knowing anything about him.
That is what it boiled down to,
It is simple,
And the judge could not deny this.

Court scared me,
What it meant for Jason,
I was never afraid for myself.
The helplessness when I thought of him,
What this was doing to him.
Not knowing where it was going,
I knew the vision was right,
Yet those thoughts kept interfering and interrupting my thought.
I would quickly go back to the promise God gave,
Hanging on to this,
Then I was fine.

Court at 2:00.
Dropped Susan off at the courthouse,
Paul and I went for lunch at the Teahouse.

It was a fluke we were there.
Paul heard them talking,
He said they are talking about my case.
"Who?"
Right behind me to my left there are some men.
I looked,
Caught this guy's eye dressed in a plaid flannel shirt,
Casual like.
I assumed they were Board members.
Going to sit in at the hearing.
I remember his hand going up and down,
Like driving home a point,
Saying, "This woman refuses to follow the School Act."
He had made up his mind,
That is why I thought he was a school Board member.
He was so adamant about this person not following the right route.

We got to court and in he walks,
He sees me right away,
Takes a second look.
I was stunned,
I turned to Paul,
Said, "That is him,
The guy in the restaurant."
He looks and realizes.
I start to pray.
I knew that this judge had already decided.
He had already made up his mind,
It would need a complete miracle to switch things around.
Poor Susan,
She didn't know what was going on.
He heard not a word she said,
She was drowning in quicksand.
No one was throwing her any help,
He was driving home his opinion about the School Act.
There was nothing she could do,
We knew, Paul and I.
At the end,
Paul goes to Susan and shares.

First case,
Thrown out.
Arguing,
The way the decision was made.
A rights issue.

Judge said she was wrong.
We were hoping,
He would put Jason into school,
Into a regular classroom,
Until it is resolved.
Judge said, "Wrong!"

I kept saying,
"God I don't understand the delays.
Don't understand judge throwing it out.
I am trusting You."

Trust in the Lord,
With all your heart.
And lean not on,
Your own understanding.
In all your way acknowledge Him,
And He will make your path straight.

One More Sign

We were finished lunch,
Paul was talking about the Camrose seminar,
With Dick Sobsey[17] blah, blah, blah,
As I reached down for my purse he says Heather.
It was like slow motion,
I looked at him,
Leaned over and said,
"Heather? Heather who?"
"Heather my wife."
There are people in this little room,
I screeched, "Heather Raymond is your wife?"
"Yeah,"
He is looking quite embarrassed,
By this little outburst.
We have been looking for her since Grade 5,
In Grade 7 she is sitting here in my lap.
It was incredible, overwhelming,
Paul's wife was Heather Raymond.
It was the biggest confirmation,
God gave me that.
I knew what we were doing was right,
I knew it was God's rightness.

---

[17] Dick Sobsey (real name) is a professor at the University of Alberta.

Round Four

Be strong and,
Do the work.

Appealing the first judge's decision,
In the city,
Back and forth.
That was hard to do,
It soon became just routine.
Sometimes more than once a week,
Preparing for discovery.

Cross examination,
They were picking us apart.
Susan started,
Sharon was cross-examined
Doing that with her,
Had she followed the rules?
IPPs without parent signatures?
She hadn't done her homework,
She hadn't done her job,
It was an oversight.
God given.
She had to be feeling foundation crumbling,
She always had such a secure foundation,
Her years of experience.
Everything just happened to our benefit,
Making her Program more wrong than ever.

Attended all examinations but a few,
Speech communication assessment,
Behaviour assessment,
Assessments supported Jason and inclusion.
Hard?
Especially Jason's Grade 6 teacher and aide.
Harder for them that I was there,
His teacher was very nervous.
Felt sorry for him.
I didn't feel sorry for his aide.

I had given the situation to God,
The whole mess.
It was God's direction.

I should have never let myself get stressed,
God promised me that this was right,
That it was going to work out.
I had no doubts.
I had no clue how,
Many times I didn't understand why things happened.
Other things that sort of blew up in our faces or complicated things.
I went to Him every time.
I have no idea what You are doing here,
I do not understand why this is,
You know how I am feeling about this,
I know that You know,
I know that You understand,
I know that You have a plan,
You look after it.
It is out of my hands.

Do not throw away,
Your confidence.
It will be richly rewarded.
You need to persevere,
So when you have done the will of God,
You will receive what He has promised.

I am a fighter.
I pushed my emotions aside,
Getting on with what had to get done,
The pain of them not hearing,
The fears of the unknown.

You feel like you are standing watching it happen to you.
You feel this town isn't yours anymore,
Like your house isn't yours anymore.
You feel like when you are walking down the street,
Everybody has an opinion and it is not supportive.
Being judged,
Thinking, "What does she think she is doing?
Why are they doing that to their son?"
A lot of people thought that it was such a terrible thing.

You don't have to worry about having enough energy,
I have all the energy you need.
I will give it to you.
The power is there,
The strength is there, God said.

I had worked through a lot of the painful stuff,
From incredible direction we get support.
I prayed seeking God.
I knew what He was saying,
I am going in front of you.
So every time there was problem,
I knew He was ahead of me.
He was taking this direction.
When you see the outcome,
But it couldn't have been,
If I had wanted it to work out any better,
If I had planned it all,
It wouldn't have been as good as it is.

Battle Won

Second summer going to trial,
New judge cared about Jason.
Going back to school for Grade 8.

He answered their prayers,
Because they trusted in Him.

They won because the battle was God's not theirs.
It wasn't my battle and it never was.
It wasn't mine,
Jason's my child.
That is the direction,
God took me,
It wasn't mine,
It was His purpose.

Return to School

When that was decided,
I came home,.
I was in shock.
It was over,
He could go to school.
I was terrified for him.
I was terrified of the hostility.
He was going back to school,
There was no doubt.
I was sitting out back,

The cold was coming inside me,
I was so afraid for him.
They don't have a clue.
They just think I am pushing them,
They have no idea,
Being a mother to a son.
Having fears like every other mother,
For her sons or daughters.
They have no idea.
When he went back to school,
I prayed for him.
I was afraid for him.
You know that fear,
All mothers experience,
Your child goes to school.
They are afraid for them,
It is an unknown,
A New World.

Grade Nine

Jason, it is amazing to me[18],
That only four short years ago,
I met you for the first time at Capital School[19].
Now you are grown,
And on your way to high school.
I am so proud of how you have done.
You have overcome so many obstacles,
Proven to everyone how capable you are.
High school has so much to offer you and,
You will bring to it.
I will miss your smiling face and,
Your hugs next year.
You truly are an amazing individual.

Jason you made the page[20].
Big funny fun things.
Nicest peer,
Biggest feet,
They recognized you.
You made the page.
They laugh and enjoy your singing.

---

[18] This was a card that Jason's Grade 9 teacher wrote to him when he graduated from junior high.
[19] Capital School is a pseudonym.
[20] Valerie is referring to the Grade 9 class memory booklet that was developed by the students.

It ended up on the page.
Like the kid with big feet.

High School

I had a phone call from the principal,
Two schedules to choose from.
It was a pleasure to be able to say,
It didn't matter.
It helps me to see,
They really want what is best for Jason.

Final Words of Wisdom

In the end it is more dangerous,
To grow up in a safe secluded protective place,
Than to be in the world,
It is more dangerous in the end.

SANDI[21]

Cameron

Magnificent,
Courageous,
Wonderful,
Neat young person.

Humanity,
Striving,
Thriving,
Informing lives around him.

Great sense of humour,
Seeing the joke in everything.
I wouldn't have it any other way,
He is my hero.

Fighting for Life

Born prematurely.
Told,
He will live to be five.
Clock ticking,

---

[21] Actual names of participants are used in this narrative account.

No expectations for schooling.

Four months,
Intensive care.
Home,
Gastric tube,
Central line,
Straight to his heart.
Gown and glove,
Sterile dressing,
Every three days.

Lucky I was a nurse.
Went on for three months.
Didn't really hold him,
Until he was six months old.
Long time to bond.

Three years old,
Pressure to think about,
Re-constructive surgery,
Less than 40% success rate.
Would have to have,
Continual surgery,
Not prepared to do that.

It is possible,
Cameron might never live,
To be an adult.
His kidneys don't work,
He will need a transplant.
At the moment things don't look good.

I don't want him to spend,
The whole of his life segregated.
It's a pretty short life,
Let's make it an important one.

The tough thing will be,
When Cameron's kidneys fail,
That is going to be the hardest time.
A kidney transplant gives you ten years of life,
Then you need another one.
There is a whole layer of debate,
I haven't engaged,

In that conversation with myself.
It is too hard,
There are so many ethical issues,
I need to confront myself.
If the solution is,
I can donate a kidney,
It could happen tomorrow.
Having been a nurse,
Seeing how families of donors are treated,
That sits very uneasy with me.
To know another child has to die,
For someone else to live.
I haven't worked out the clarity,
Where I fit in all of that.
I am just hoping,
That Cam and I or his dad,
Will be compatible enough and,
Cameron will be old enough,
To take an adult size kidney.

This year he's on,
Blood pressure tablets.
They think,
Another five years of life in the kidney,
I am hoping if they say five,
We have ten.

This is part of my life,
Not giving up on Cameron.
He has not given up,
That is my driving motivation.
If he can fight,
I can fight.
I make every day,
As full as it can be.

Isolation

Eighteen months old,
Moved from South Australia.
I had had my family,
My connections.

Queensland.
Never felt more isolated.

Knew no one.
Time to find my feet,
Relationships,
Therapist,
The only people I talked to,
For six months.
I was so lonely,
Bone aching lonely.
I usually had a big network,
Friends and activities.

Cried regularly,
Usually didn't steep to that.
Getting services,
Finding a way in the world,
Driving me crazy.
It must be equally,
The same for other people.

Heard speakers describe,
"Circle of friends.[22]"
Set me on the road,
Building a better life,
For Cameron and me.
I went out of my way,
Talking to people,
Being more friendly than usual.

Disability Studies

Decided,
Research,
Write a book,
How other families had done.
Letters to families through three services,
Interviewed thirty families.
Captured their stories.
Never printed it,
Sits on a disk at home.

Stories of incredible courage.
Talked about everything in life,

---

[22] Snow & Forest (1987) describe a process for building a "circle of friends" around a student with disabilities. To read about the process see Snow, J. & Forest, M., (1987). Circles. In M. Forest (Ed.), *More education integration* (pp. 169 - 176). Toronto: G. Allan Roeher Institute.

Sexuality,
Education,
Work,
Social.
Broadened my perspective.

Tanya,
Young woman with cerebral palsy.
Story of going to a special school,
Year eleven was counting the number of birds on trees.
Remarkable young woman,
Thinking,
Modifying curriculum,
A challenge for the teacher.
Finished school.
What kind of workshop do you want to attend?
Not what her life was about,
Started high school at eighteen,
Got top grades.
Now in university,
Studying to be a teacher.

Thirty stories,
Made me think,
What should education look like for Cameron?
Took a serious look at special education,
Probably wouldn't have done it otherwise.

Nudging

Cameron went to a special education development unit,
For therapy and stuff.
Teacher said to me,
"You need to find out about inclusion,
Look around,
Cameron will bloom in a regular class,
Never send him to a special school."
She was a "special" educator.
Got to know her,
We are good friends.
Daughter had measles,
Developed syndrome linked to intellectual disability.
She had a different vision of the world,
She directed her kids to regular education.
Told me that it was time,

I got involved in the parent advocacy group QPPD[23].

Why Inclusive Education?

It sort of happened eclectically,
A bit synchronously.

Early Intervention

Cohesive group of workers,
Powerful team.
Wonderful women and man,
Had the same worldview.
Made a difference in the lives of families.

One woman, Jan,
Inspiration to me.
Her practice was to challenge us,
Asking why would you make that choice?
Get to the core,
What are you looking for?
Talked things through,
To get a clear picture.
Developed respect for each other.
Through her I was crystal clear,
Why inclusion and what it took.
These were some of the people,
That stood beside me,
In getting inclusion.
Powerful advocates.

Advocate[24]

I have this history of being involved in community.
Jan and Marianne lobbied me to be the president of the,
Parent Early Intervention Support Group.
They saw me differently than other parents,
They knew I could be challenged,
They encouraged everyone,
But I really took it up.

---

[23] QPPD stands for Queensland Parents for People with Disabilities, which is a parent advocacy group.

[24] Throughout the telling of her story, of securing inclusion for Cameron, Sandi shared her experiences with advocating for system change and her concerns with the present education system. Positioned beside her story of her son's inclusive education experiences I have positioned, in a different font, Sandi's narrative of system advocacy.

They would ask me to talk,
At training sessions for therapists,
I would tell them the importance of,
Telling people about options,
Not just segregation.
I wrote lots of letters to politicians,
Got to know my local politician really well.

Speakers

Sat on the fringes of QPPD.
CRU[25] a series of paper bag lunches,
Listened,
Heard an international expert,
Talk and show a child,
Being tube fed on the playground,
By other children.
Thought if children are capable of that,
It is limitless.
Asked another speaker how do I get it,
Said, "You need to talk to QPPD."

Decided

Cameron was 3½ or 4,
It was time to think about school.
I decided everything my other kids had entitlement to,
I wanted their lives to be,
I wanted Cameron's life to be.
I wanted it filled with friends.
I wanted him to be part of his social community.
I wanted him to grow up,
To be loved,
Have relationships with other people,
Job he has passion for,
Nothing different.
So that meant,
Education didn't look different either.

I don't want crumbs for Cameron.
I want him to enjoy the whole pie of life.
I don't want him to have just the morsels,
Education is prepared to give.
I want him to be at school.

---

[25] CRU stands for Community Resource Unit, an advocacy group in Brisbane.

I want him to learn,
Not sitting staring at the walls.
I want all of it.

Local School

Went to local school.
Principal said, "You know,
I just don't think we can accommodate."
Went away thinking,
"Okay,
If that is the mindset,
I need to get informed,
Exactly why Cameron should go here,
What it means,
What it takes,
How teachers teach."

Educating Myself: Knowing The Language

I trained as a registered nurse,
Learned the language of medicine.
Needed to understand how to use it.
Whole heap of people,
Couldn't have that conversation.

Language of education,
I knew the silence,
Most people do not understand it.
I could understand,
Use it the same way that they used it.

Spent a year,
Learning the expert language.
Read everything on inclusive education,
To feel strong enough to have the argument,
To understand the language of education,
To know how to use it,
To never sit in a meeting,
To never feel I don't know the answer.

I worked hard filling up the tank of knowledge.
It feels like you are,
Dictated on this journey.
Means my free time,

Reading about curriculum,
Research reports.
Would be nice to study art or something else.

Fellow Parent Support

Early in the journey,
A friend of mine in Queensland,
This wonderful gorgeous person,
I love to pieces,
She knew more about the Education Department policy,
Than the Department knew.
Her daughter has just finished school.
Elaine is a very centred calm woman.
She would go to her meetings,
She would say what she wanted up front.
Everybody would talk for hours,
Before they left she would say,
"Can we get back to my point?"
She would always win.
I would ring her all the time,
Saying, "What do I do here?"

Because I was part of QPPD,
I heard wonderful stories of other families,
Inspired me to never give up on Cam.
I started on the journey insecurely,
Knowing what I wanted,
Not knowing how to say it.
Being part of QPPD gave me connections,
Other moms and dads,
Who fought for their sons and daughters,
It gave me an avenue to fight.

Preschool

Worked to get Cameron into the preschool,
It was on the school grounds,
The school all the kids go to.
The local school my older son went to.

Ascertainment[26] Meetings

Policies say they are about,
Helping schools understand,
What they need for your child.
Actually government telling parents,
What they are allowed to have,
For their sons and daughters.
Two years of meetings,
Finding all the deficits in your child.
Confronting.
After two to three meetings,
Most parents give up,
They are structured exactly that way.
It is only really stubborn nuts,
Like me that go on to fight it.

Loss of a Friend

During this time Jan passed away,
We all really felt it.
Bernie, her husband, had always been,
Close to our organization.
He came to us and said,
"I want to continue her work."
He became Cameron's advocate.
He had worked for Treasury,
He had this presence about him.
Came to all the meetings with me,
Everyone thought he was my lawyer.

---

[26] "The ascertainment process is based on educational need arising from a disability. Ascertainment is initiated when staff or parents at an educational facility consider that a student with a disability may need specialised educational services and support. It is a decision-making process to access the educational support needs of a student with a disability. Parents, teachers and statewide moderators are involved as team members in the process in which a recommendation and ultimate decision are reached concerning each 'ascertained' student regarding the level of program and specialist support required. Students may be ascertained in one or more of the following six areas: physical impairment, vision impairment, hearing impairment, intellectual impairment, autistic spectrum disorder or multiple impairment. The levels of support range from 1, where there in a low level of educational support required, to 6, where educational support needs are high. Students at this high level of support are placed on alternative educational programs know as Individual Education Plans (IEPs). Ascertainment data, determine in this way, informs the allocative mechanism which the Queensland Department of Education uses to apply to its State Treasury for funding" (Hamilton, R., 1997, p. 120). Supporting students with disabilities in school: Keeping the focus on educational outcomes. In Cormack, M., Willis, K. & Winter, P. (Eds.), *Effective funding for children and students with disabilities - towards a new practice* (Volume 1, pp. 117 – 162). This is an action research report prepared for the Ministerial Advisory Committee: Students with Disabilities SA, Department of Employment, Education, Training and Youth Affairs, Adelaide, SA.

I never told them any different.
He sat, took notes through the meetings.

The Guidance Officer[27]

That was part of the process,
Over the two years,
Rung me at home after hours,
Trying to talk to me about,
Inclusion not an option.

The Guidance Officer dropped into the preschool,
She thought having a series of really long talks,
I would give up on inclusion.
It had worked with other parents,
So why didn't it work with me?

If you have the same conversation,
A thousand times,
People give up.
I was sure what I wanted for Cameron,
It was not what the Guidance Officer wanted.

IQ Test

They wanted an IQ test done.
I refused to let the Department do it,
It would be done by one of my friends.
The report,
Supported inclusion.
They were really cross,
It was not what they wanted.

The Guidance Officer spent a heap of time,
Telling me Cameron's IQ wasn't high enough,
To go to a regular school.
We spent hours.
I just sat and listened to her,
And got more pissed off with her.
I had to give her the time,
To appear reasonable.
I kept saying no,
It was really frustrating.

---

[27] In Queensland, Guidance Officers are teachers with 3 months additional training who coordinate the human resources for children identified as having special education needs.

Conversations had nothing to do with Cameron,
Had to do with her stereotyping kids with disabilities.
It didn't reflect Cameron at all.
She wasn't even prepared,
To engage in knowing him,
As a person.
She just wanted to do her job,
Which was to tell parents,
Their children can't go to regular school.
She did it really well.
It worked for most.
Every once in a while she would meet one or two,
That didn't want to go down that path.
People spent more time and energy,
Talking to me for two years,
Trying to convince me.

The Decision

November,
Before Cameron was to start school,
Arrived to an Ascertainment meeting,
Seventeen people,
In the principal's office,
With a desk that takes up 90% of the room.
Seventeen chairs in a space this size.
November Queensland is hot.
Bernie and I sitting there,
Every person went on to tell me,
The deficits Cameron had.
Why it was absolutely impossible for Cameron,
To attend regular school.

Thank goodness an early intervention worker was there,
She said, "Cameron has good signs of early literacy."
There were three of us fighting for Cameron.
Everyone else was saying, "We think it is impossible."
The meeting lasted 2½ hours.
I was really angry,
I try hard in meetings not to get emotional,
I think you lose it,
It was really hard.

Bernie said,
"I am the father of four children.

There is not one time in my children's lives,
That I have ever sat through such a disgusting event.
I think you all should be ashamed of yourselves."
That was powerful.

When we got out of the room,
They said , "We better give you a cup of tea."
They rip your guts out,
They placate you by offering you tea.
We left.
Bernie said, "I am really pissed,
We are going to do whatever it takes."
We stood together firmly.
After the meeting,
They went on to write a series of reports,
The deficit model.
Reports made me angry,
Never identified Cameron as a human being first.

Dispute Model

Study[28] on 1,307 complaints.
Made under the DDA.[29]
Three hundred went on to a hearing,
To a complaint process.
Two of these were settled with,
The people with disabilities,
Happy with the outcome.
They all said they would not use it again,
Kids are out of school for five years.
How can you re-establish back in school,
Five years after the event?
You can't.
The dispute model does not work.[30]

One Woman Decides

I was fussed about this,
There was to be a woman,

---

[28] Jackson, R., McAfee, J. & Cockram, J. (1999). *Disability Discrimination in Education*, Discussion Paper, Centre of Disability and Youth Law, Edith Cowan University, Joondalup.
[29] DDA stands for Disability Discrimination Act (1992) issued under the Commonwealth government. The DDA seeks to eliminate discrimination as far as possible, against people with disabilities.
[30] Sandi does not see the dispute model as viable in determining student placement choices because of the long drawn out process and the negative effect it has on families.

Who would have a telephone conversation with me,
Telling me what school Cameron was allowed to go to.
She would give the label.
She never met Cameron.
She would get expert information.
She would decide.
I was to sit and let that happen.

I wrote a critique of all the reports,
Pulled them to pieces,
Pulled out all the inconsistencies,
Everything that did not make sense.
Made a video of Cameron with the family,
Sent it to this woman.
If you are going to pass judgment on my son,
Then you should have some context as to who he is,
You can't do this in isolation.
The family and Cameron are part of the community,
We have strong links with the community school.
Cameron and I did Tuck[31] shop at school,
All the kids knew Cameron.
Nobody talked to his brother,
When we walked into the school,
Everyone just said, "Hi Cam."

I thought that they were going to fight for a Level 6[32],
In Queensland with a Level 6
You are really only allowed to go to a special school.
We had a meeting,
It was meant to be a conference call,
But the telephones did not work.
This woman got on the phone,
She said, "Hi my name is….",
I said, "I am checking,
Did you get my video and information?"
She laughed,
She said, "Yes I did,
It is quite a powerful statement."
She went on to give Cameron a Level 5.
Which meant he could go to the local school.
We had just got our foot in the door,
After two years,

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[31] Tuck Shop is a school store that sells food treats to the students during the recess and lunch break.
[32] In Queensland students with disabilities are coded based on the level of support they need as well as the type of program the State Education Department determines a child needs.

That felt like thousands of hours of meetings.

Funding

I think one of the big problems,
With the Education Department is,
They have to stop telling lies to parents.
I have been trying for years to track funding,
They really in essence have enough money.
There is a special arrangement,
Called National Strategy for Equity in Schooling[33].
The funding is meant to come to the child with a disability,
It is about equity funding,
It is additional funding.
What happens,
The money goes from the Commonwealth,
Into the state,
It is really hard to know what happens to funding then.

Allocations

Kids get allocated,
Let's say five hours.
They say that is all you are allowed,
That is all the resources,
In the Education Department,
For that child no matter what.
So you can take that five hours,
Go to a special school,
Where there are a whole heap of other kids,
There will be hundreds of hours of aide time.
Or go to your local school,
But you still only have five hours.

Parent Opposition

They gave us permission,
For Cameron to go to our local school.
It was a small school,
With 125 students.
It was a real close community in a nice way.
I was on a school committee,

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[33] National Strategy for Equity in Schooling (NSES) - The needs of students in equity groups identified in the NSES were addressed in 1997 through a range of school-based, regional and system-wide initiatives funded through both State and Commonwealth sources.

One night we had a meeting,
At my house.
This woman sat at the end of the table.
She was a parent of another child in the school.
She had a teaching background.
She said, "I want to know if you are going to continue,
With this ridiculous notion of including your son at our school.
It makes absolutely no sense,
And if you are I am resigning from this committee."
I said, "Yes."
She said, "I resign" and walked out.
I thought, "This is doomsday,"
I sat with knots in my stomach.
My friends said, "Glad you did that,
We couldn't stand her."
We had this amazing conversation,
Why we chose inclusive education.
Everybody walked out with a real sense,
We will support you to do this.

Her other tactic was,
She actually met parents one-on-one.
Telling them in the playground,
It wasn't going to work,
They had to lobby the principal,
To not let it happen.
I said to the principal,
"You need to tell her to stop,
Or I will take her to the anti-discrimination board.
Tell her to be quiet yesterday,
I don't want to hear it any more."

Principal Opposition

The crux came between he and I,
When he refused to allow Cameron to attend pre-school full-time.
I went out and organized a volunteer program,
To support the school with teaching Cameron full-time.
He said, "No."
He said he was not going to have them.
I said, "We'd see."
It happened,
I went and did what I needed to do,
To make it happen.

Right Decision

The principal and I had this conversation,
If he had a child with a disability,
He certainly would do the right thing,
That would be special education.
I said, "I respect your choice,
But it is not your choice.
I am asking you to follow the Education Department policy."
He said, "There is no policy."
"There is a policy,
It is this document,
Here it is and this is what it says."
I knew more about the policy than he did,
It just destroyed him.
It was the straw that broke the camel's back,
Between him and me.

Policies

Policies are attached to illness,
The medical model.
The Department will pay,
The hours a child needs for duty of care.
But will never give,
More than two hours for curriculum support.
I would have thought,
But maybe I am a complete lunatic,
What you actually would put your money into,
Is education.

One More Hurdle

The principal organized a meeting.
It was a forum for parents,
To discuss Cameron's enrolment.
It was advertised,
On a flyer,
In every child's pigeonhole except mine.
Obviously thought I was isolated in the community.
Friends told me about it,
Had some really strong relationships,
With other women in the community.
I was angry.
I went.

Felt like Daniel going into the lion's den.
Promised myself,
I would be calm,
I would be patient.
Nearly every family was there,
Fathers as well as mothers, really unusual.
The principal did a better job of managing it,
Than I thought he would.
Can't remember the specifics of the conversation,
But I spent a whole heap of time listening,
To people's concerns,
Which he addressed really well.
He talked about Cameron's aide,
Being there to support all the children.
The teacher was there too.
Really interested in having kids with disabilities in her class,
Talked about her experience of including other children,
Felt really positive about those experiences.
I spoke at the meeting.
Said, "I was happy to engage in conversation with parents,
If they were having problems,
If there were issues needing to be addressed.
I was open to listen to them,
I would be around to support Cameron,
We would work as a community to make it happen."

Public View

For two years I felt like I lived in public view.
Everything I did was in the public forum.
I was on this island,
That was different from the rest of the world.
Other people wanted the same.
I knew it wasn't different,
I could say to the Education Department,
"I don't want anything more for Cameron,
Than what has been given to other children."
I had a network.
I was tired.
I was frustrated.
Glad I had heard a speaker say,
"You have to say the same thing,
Over and over again,
Until you are vomiting.
That is what it is like,

If you are not nauseated,
You have not said it enough."

Resources

All the planning,
When a kid starts school,
We should not have to argue,
Every single year for resources.
It should be this is the child,
They are here for seven years,
What do we need for the next seven years?
Instead of going to bat for aide time each year.

Starting School

Grade One

Cameron started school,
A week later than everyone else.
His teacher was a stunning woman.
We became very close.
Her nephew has autism,
She used to come to me and ask, "What do I do?"
She was doing a masters in special education.
I gave her a stack of information,
Keen to talk to overseas expert,
Helped her get ahold of him.

First year of school was a struggle.
I had to do two lunch breaks,
Wanted me on the playground supervising Cameron.
There was this negotiation that happened in my private life.

Teacher and I worked hard together,
To make it work for Cameron.
We always had long conversations,
I made sure I was always available,
If there was a problem we found the answers together.
I worked hard at supporting the school,
I spent 90% of my life there.

There was a really good teacher aide,
They got on fantastic.
That made the whole dynamics of the classroom,

Work really well.

Moving

Half way through the year,
My husband decided to leave our marriage,
Really changed the dynamics of our family.
Time to come home to South Australia,
To be close to family that could support us.
Tough decision.
Part of me knew to stay in Queensland,
Would be an Ascertainment review every two years.
The pressure would be,
Put him in a special school.
At least in South Australia,
They still believe it is the parent's choice,
Where you send your kids to school.

Special Education

There is nothing in special education,
That reflects education,
It reflects institutional care.
It comes from the ancient Greeks,
People with disabilities were not the same as us.
People were charged with,
Congregating and collecting these people.
They don't have a clue,
How to look after these people,
They just know how to
Abuse, feed and clothe them.

Cameron's Presence

The last day of school,
Driving back to South Australia.
I picked up the boys at school,
They said good bye to all their friends.
The principal came out,
He was new to the school that year.
We had had lots of discussions and negotiations,
But he thought I was a hero,
I had written a submission,
And got computers into the school.
He stood,

Looked at Cameron,
Said, "My life will never be the same."
Fighting back the tears,
He hugged me,
And said,
"You leave footprints where you go."

That is the purpose of life,
If we don't leave footprints,
Nobody knows we've been there.
That is my role,
Cameron's mom,
It is up to me.

Researching Schools

Before I left Queensland,
I did a heap of research,
Where to go in Adelaide.
Met with an advocate from Adelaide,
Said, "Tell me what you know about schools."
Had a clear picture where we would settle,
I got a house in the school area,
That I knew would have Cameron.

Local School

I went to our local school.
Walked up and said,
"These are my three children,
They are coming here."
I talked to them about Cameron,
They said, "Okay,
What do we need to organize?"

Grade One Again[34]

Cameron started a week later.
I said, "By the way,
I am not going to be here to do this."
I was doing a full-time degree.
"I am here to support you guys,
But I am not going to be here,

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[34] Upon returning to South Australia from Queensland all Sandi's sons were required to repeat a grade.

Every five minutes,
Like I was in Queensland."

The teacher that had Cameron,
A wonderful human being,
Worked hard to do everything,
To include Cameron.
She did everything she could to make it happen.
We sat together,
Worked out curriculum.
The first year was really positive.

It was good,
Because I struggled personally,
To make a degree that first year.
That was really hard.

University

I went to university with the concept,
I have to jump these hurdles,
To get a job to write public policy.
I am really tired of crappy policies,
I want to make different policies,
That bring about a better life and society.

I had to rebuild my relationship with my family,
Connect up with old friends,
Make new friends,
Boys had to make new friends too.
It was a busy year,
But we did it,
We survived.

Grade Two

The teacher at the end of the year,
Decided she wanted to have Cameron,
For another year.
I felt oohh…
I didn't know but I said, "Yes."

The second year,
The teacher worked hard,
She got Cameron a laptop computer.

She kept asking the Department[35],
For resources and help.

What makes me cross,
In South Australia,
They have this fabulous policy,
Rhetoric about inclusion,
But they actually have no expertise in people,
To support teachers to make it happen.
The teacher would say,
I need an answer for these questions,
She would get a deafening silence.

By the third term of Cameron in her class,
It was driving her crazy.
She kept saying,
I am not getting the answers,
I need as a teacher to support me.
I felt that was true,
The people in the Department,
Called Disability Support Officers,
I wonder what their skills are,
Every time she asked for support,
They didn't have any information or ability to support her.

Walk the Talk

Policy writers take the inclusion focus,
But if you went to those people,
To get it to work,
You would not get anywhere.
I have this theory,
You should not ask someone to do something,
You can't demonstrate you can do yourself.
You must walk the talk.

Teacher Wavers

In July the teacher said to me,
"I want you to think about next year,
Cameron going into Reception[36] in the morning,
And a Grade 3/4 in the afternoon."
I was really taken back.

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[35] Sandi is referring to the Department of Education.
[36] Reception class is equivalent to Kindergarten in North America.

I knew she was getting increasingly stressed,
By the lack of support.
But what inevitably happens is,
The child and the family,
Is the brunt of that frustration.
It is a system problem,
They don't actually support teachers to support kids.

I said, "I couldn't respond to this,
I need to go away and think."
I said, " I could give you research,
Why you shouldn't do that,
Will you listen?"
They said, "Fine."
We had a sort of one off meeting,
I said, "My position is really strong,
I want Cameron to be included,
These are the reasons.
But I want you to understand,
I am offering you people that I know,
That could come to the school and work with you."

I called an advocate and he said, "Call Darrell[37],
He is the only person I know,
That can talk to schools about curriculum."
I called Darrell and said,
"You don't know me from a bar of soap,
But this is who I am,
This is what I need…"

It happened he was coming to Adelaide,
To do some research.
He went to the school with me and met the teachers.
I don't think the teacher spoke to me for six weeks,
Because Darrell gave them all the reasons they could do it.
It wasn't what they wanted to hear.
They were angry.
They had gotten a letter from me,
With a heap of suggestions from Darrell.

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[37] Darrell Wills, BA/M.Ed., Project Director and Education Consultant PLEDG Projects. PLEDG stands for, "Parents Learning Education Development Group." PLEDG is governed by a Board made up of parents of children who have been or at risk of rejection. The Board determines which project they will work. The goals and vision of the PLEDG Projects are designed to support the positive inclusion of ALL children in their local, home schools. Their vision is to build wholesome communities where everyone is welcomed and included.

There was this big drama,
How could you let these people into the school?
How did they get past the Department?

More Than a Mom

I got appointed as the Disability Representative
To the MCEETYA[38] Task Force,
To review the DDA Standards for Education[39].
Really interesting dynamic for the school,
Suddenly they have this parent who has a say,
At this senior policy writing forum.

Grade Three
My life got really busy,
I stopped focusing on Cameron's school.
Every now and then I would lift my head up,
And see how it was going.
I noticed Cameron still had the same ten words
On his DynaVOX[40] that he started the year with.
I went into the teacher,
And said, "Look I really have some concerns."
She said, "Cameron doesn't know them."
I said, "If you had the same ten words for six months,
Would you still push the buttons?
Tell me one other child in the class that you would do this to?"
She just had this really blank stare.
I thought it is almost like they don't apply,
The same rules and principles of education,

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[38] MCEETYA - Ministerial Council on Education, Employment Training and Youth Affairs comprises the State, Commonwealth and New Zealand Ministers with responsibility for the portfolios of education, employment, training and youth affairs. MCEETYA's ongoing work is undertaken through a number of task forces that have clearly defined terms of reference and are subject to annual review.

[39] DDA Standards for Education are issued under the Commonwealth government. Education and training constitute a service covered by the DDA. Education authorities, institutions and providers are obliged to provide the services and facilities necessary to ensure that students with disabilities can participate in education and training without discrimination. Following an extensive consultation process in 1997, the Task Force worked to specify Disability Standards for Education. The Council subsequently agreed that further work was required to develop a draft combining both principle and performance-based standards. The Standards would also need to meet the legal requirements of standards under the DDA, and secondly, to give guidance to both education and training providers and students with disabilities, or their associates, as to what would count as compliance with the DDA. During the year 1999/2000 the Standards had been extensively redrafted and address five key areas. These are: enrolment; participation; curriculum development, accreditation and delivery; student support services; and elimination of harassment and victimisation. At the 11th MCEETYA meeting in March 2000, Council agreed to the further development and implementation of a consultation process with key stakeholders and to use the draft Standards as the basis of this consultation.

[40] DynaVOX is an electronic communication device that Cameron uses to communicate.

To kids with disabilities.
I got this spelling book we used at home,
Why don't you generate a list from here?
That never happened.

Opportunity to Teach

In a subject[41] Social Policy Analysis,
Our presentation had to be on a subject,
We were passionate about.
A friend and I decided,
We were going to talk about the history of disability.
Then we got four other people in our group,
Who were loosely interested in disability issues,
Not the passion of having a child with a disability.
The first three weeks when we met,
We couldn't agree on anything.

One week before semester break,
They decide,
We are going to do,
The day in the life of a person with a disability,
A woman with a mental illness,
That had her children taken away.
I said, "Did you for one minute,
Stop and think,
The stereotyping that you have done,
In that one single statement?"
I am not very good at being quiet.
"You have just fallen into the trap,
Assuming because she has an intellectual disability,
That she cannot be a parent.
I can actually take you to friends of mine,
Who have intellectual disabilities,
That are fantastic parents."

So they decide,
Someone will do IQ testing,
Someone would do education,
Someone would look at employment,
Another empowering approaches of social work,
And applying it to people with intellectual disabilities,
And Agatha and I would do the history.

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[41] Subject is the Australia term for a university course.

One girl had her placement,
In the Children's Hospital,
Working in the medical model.
She felt the answer was IQ testing.
I said, "Fine," through gritted teeth,
"I don't have a problem with that,
As long as you read these three books:
Mismeasure of Man[42],
Is there a desk with my name on it?[43], and
The man who mistook his wife for a hat[44]."

The guy doing education, Terry, said,
"I can't find any research on inclusive education."
I said, "Wow that is a really powerful statement,
Because we are sitting here in a university,
That teaches teachers."
He said, " I never thought about that."
He went on to talk to me about,
He would never send his children,
To a school with kids with disabilities.
I said, "I will have that conversation with you,
When you get knowledge.
You need some research,
Come up to my house,
I will give you a heap."

The girl doing employment,
Said, "I can't find anything."
I said, "Ring my mate up,
He is working on employment standards
In Canberra[45].
He will talk to you about the current legislation."

The next meeting,
The girl that wanted to do IQ testing,
Came back and said, "I can't do IQ testing.
I just figured out that it is a social construction."
I thought, "Yes!"
She said, "I am going to talk about.

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[42] Gould, S. J. (1996). *The mismeasure of man.* New York: Norton.
[43] Slee, R. (Ed.), (1993). *Is there a desk with my name on it?: The politics of integration.* London: The Falmer Press.
[44] Sacks. O. W. (1985). *The man who mistook his wife for a hat.* London: Duckworth.
[45] Canberra is the national capital for Australia where the Commonwealth Government Departments are located.

Recreation and people with disabilities."

Terry came and said,
"I can't believe I used to think that way."
Good!
Then we had a conversation.
I gave him a couple of articles,
One of them was Dick Sobsey's[46] article.
A critique of special schools,
It was just so powerful.

In that group process,
Only one person got the main message,
Disability has been created by society.
If you get born with a label you are stuck with it.
Society is going to define you that way.
Terry said to me,
"If you had not been there,
I would have learned nothing."
I see my time at university,
As a time teaching other people,
About bigger issues.
Like the tutorial group,
I saw that as a window of opportunity to influence.

Cameron's Learning

People assume Cameron is not learning,
Due to his lack of speech,
Because they don't test,
What he is learning in a non-verbal way.
I watch him with Darrell,
Who is a natural teacher,
Cameron just sits when Darrell is around,
Tell me more,
Tell me more kinds of things.
He knows Darrell will take him seriously,
Taking time to speak to him.

They had this conversation thousands of miles away,
Darrell figured out that they had a lesson on coal,
On the phone with a non-verbal kid.
Darrell said, "I haven't been around you for a while,

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[46] Sobsey, D. & Dreimanis, M. (1993). Integration outcomes: Theoretical models and empirical investigations. *Developmental Disabilities Bulletin,* 21(1), 1-14.

It will take me some time to get used to how you talk,
So just take it slowly."
In fifteen minutes he knew Cameron's whole day.
Darrell teaches me Cameron understands.
It was a surprise to the school,
They didn't know he knew that.

School Bullying

I noticed this year Cameron,
Did not want to go to school.
I complained a lot about that.
The year seven kids tease the younger kids,
It is a big problem in the school.
Cameron often gets teased on the playground,
I kept saying we have to do something about it.
If you need me to come and talk,
To the kids who have problems with Cameron,
If they just need to spend time with him,
Learning how to interpret him,
I will be around to facilitate that.
But it never happened,
I get frustrated about those kinds of things.
I think they see me,
Very much like a difficult parent,
Who has huge demands. .

University and Advocacy Do Not Mix

Tutor said, "Sandi, I want you to do a placement,
At the Minister's Advisory Council for Special Education.
You know all the issues.
You have the experience.
You're perfect.
My friend works there,
I will get you an interview.
She will be delighted to have you!"

I thought they wouldn't accept me.
I wandered off thinking,
This would be a really good place,
To influence,
If I get my placement there.

I don't believe in telling lies.

I said to this woman,
"You need to know who I am.
I do this,
My position is,
I believe in inclusive education,
There are no exceptions.
You need to know,
I have lobbied the Minister.
I sit at MCEETYA."
She asked, could she read some of the stuff I had written.
Packaged it up sent it off to her.
She rang me and said,
"I am really disappointed,
I have to make this choice,
But the Minister decided,
It would be too uncomfortable,
To have you as a student."

Placement

I did a placement at Independent Advocacy[47],
I took on the role of advocate to other parents.
That was a really good year and practice,
Spent time with other parents,
I ran workshops for parents,
Why you would choose to include your child.
And a heap of other things.

Crisis

I was on a national advocacy tour,
My boys went to Brisbane,
For two weeks,
To be with their dad.
When we came back,
Cameron did not want to go to school.
The second day back I picked him up from after school care,
The coordinator said, "Something is really wrong,
Cameron cried the whole hour."
He was really distressed.
We went home,
He cried for another couple of hours.
Then I made sense of what had happened,

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[47] Sandi is the president for the advocacy group called Independent Advocacy. This is a not-for-profit group that advocates on behalf of individuals with disabilities and their families for community inclusion.

The boys had been away from school,
Cameron was really nervous of going back.
It had been a sports day parade,
The aide must have gotten angry with Cameron,
For walking with his brother who is in a younger class.
She set him by the collar of his shirt,
And pulled him back to where she wanted him to stand.
That totally undid Cameron.
I knew the relationship between these two was getting worse.

Concerns With the Aide

I have a problem with,
Aides being attached to kids for three years.
Aides are used really badly in South Australia.
I kept him home for five weeks.
I needed to think about how I was going to manage this.
I talked to lots of kids in the class.
I talked to the therapist that came into the class.
I got this picture that his aide had been left,
To do curriculum modification with Cameron.
This was stressing her,
She had no qualifications.
Initially she was a really good supporter of Cameron,
Things had gone wrong.

Cameron was sick of her.
Monday Cameron has no aide.
It is his favourite day of school,
He loves it.

I wrote a letter.
I had to maintain the balance,
Between complaining about what happened,
Putting safeguards in for Cameron,
Saying the aide is not going to be there next year,
And keeping a relationship with school.
It took me a while to figure that out.
Last Friday of the term, the end of that week,
The principal called me and said,
"That is quite a letter."
I had spent hours, agonized over it.

We made an appointment,
We had two meetings.

We talked about managing stress,
We have to get clear about whose role things are.
Bottom line,
Aide is not alone with Cameron.

Aide's contract ends,
She is finished.
I would not send Cameron back to school,
For as long as it takes,
Until we get a male teacher aide.
That is my ultimatum,
That is my bottom line.

NCP[48]

They gave me Cameron's NCP,
After that meeting.
They should have given it,
At the beginning of the year.
It made me think,
Why is it that you have to complain,
To get what is reasonable?

We have beautiful documents called NCPs.
If you are going to have an NCP process,
And it means anything,
You have to use them.

I asked the special education teacher,
"Did you read the NCP,
That was written last year?"
Why waste my time.
I am a busy person.
They are busy people.
They don't use the NCPs.
I see them as another waste of resource time.
You waste all these resources in setting up a meeting,
Wasting the teacher's time,
Wasting the parent's time,
Wasting the principal's time,
To write a document that goes into the filing cabinet.

I see NCPs as a form of exclusion,

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[48] NCP is a Negotiated Curriculum Plan, which is called an IPP Individual Program Plan or IEP Individual Education Plan in North America.

School will say it's pretty obvious,
We can't have this child here,
They haven't met their goals each year,
They need something special.

Because of the drama,
At the end of the year with Darrell,
They thought I was a lunatic parent,
Wanted the impossible.
They wrote down everything,
In every single subject[49] in his NCP.
Twenty pages,
I thought, "Brilliant,
I am just this neurotic parent,
Who if reasonable,
Would have already gone to special education."
She is still bitching about how the world goes,
Why can't you do this?
What sounds like logic to me seems not at all like logic to them.
I think we live in two different worlds.

Standards

Nothing in the DDA Disability Standards for Education,
Will bring about long-term system change.
We went to a meeting,
The process talks about participation.
We said,
"We want inclusion,
We don't want participation,
Participation does not guarantee,
Full membership in the,
Social,
Curricular,
Physical,
Environment in school.
It has got to be inclusion."
The guy from New South Wales said,
"We are not writing that.
If we put the "I"[50] word in there,
We will have teachers' unions,
On strike across the country."

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[49] The school had written into Cameron's NCP all the learning goals for Grade 3 students rather than selecting a few goals with adaptations for Cameron to accomplish.
[50] "I" word is inclusion.

Committees

This is the stuff that bugs me.
This is what takes the money away,
From kids with disabilities,
Being supported in regular schools.
The director of special education resource unit,
Set up seven committees,
They are all paid people.
We don't need more committees,
To know how to include kids,
We know the research that is there,
We don't need to keep asking the same questions.

System Divides

What happens in education,
And the disability sector is,
We spend all our time and energy on,
What divides us.
We have this argument,
Why inclusion?
Why not inclusion?
I want to get to the point,
Where we have conversations,
With teachers' unions.
About what teachers need to have my son at school.
Actually working together to make that happen.
I want to have conversations,
With the Education Minister,
How to make schools accountable?

Juggling The Balls

I didn't wake up,
To how crappy things,
At school were for him,
Until too late.
The year is nearly over.
It makes me wonder,
How I have to manage that.
The reality is I need to work,
To support the boys,
I have to have a better quality of life.

I haven't come to the answer,
How to juggle all those balls.
Darrell and I had a really long conversation,
He really believes parents as teachers,
It makes a whole lot of sense.
Our kids are not being taught at school,
So we need to do it at home.
So I need to take that up,
I need to find another ten hours,
In my week to tutor Cameron.
I wonder how I will manage and maintain that,
To raise three kids on my own,
To finish a degree,
Find the time and energy to tutor Cameron.

Unreasonable Expectations?

I expect them to teach my son,
Not just have him sitting in the class.
I expect them to make a social network for him.
Not extraordinary curricular things.
I see a mix between a parent's perspective of good inclusion,
And an educator's.
We don't discuss those,
That is a problem.
My school would think,
They are doing a good job of including Cameron,
They do on one level,
But not on other levels.

Reading and writing are fundamental things,
Numeracy and literacy are what we teach best in regular classrooms.
Loads of kids just trace their name,
Count the number of the birds in the tree.
Schools don't get it,
The kids have just as much right to be challenged,
And to be frustrated by the curriculum as other kids.
They believe kids should be there,
In the scheme of Adelaide they do.
They have about 15 kids out of 300 with disabilities,
Which is more than I see in other schools.
They have a commitment in social justice,
But they don't have the technical skills.

Tokenism

Here in South Australia,
Inclusion is token stuff.
You can have inclusive education,
But there is no support to teachers to make it happen.
There is no support for parents,
Parents often feel isolated in the education system.
When it comes to high school,
Everyone drifts back to special education.

Equity/Equality

In Australia at this moment,
We are seeing a shift,
In the concept of equity and equality.
Policy makers are using the term equal,
Rather than equity.
Saying we treat everyone labelled,
The same,
Equally.
Equally is not equity.
Equity is about bringing those below,
Equal to the norm.
We have lost the desire for equity in policy.

Token Consultation

Independent Advocacy,
Got asked to critique a review of curriculum.
They presented this folder,
That was this thick.
She[51] said, "Any comments?"
I said, "I want to read it."
"No!"
"Is it a public document?"
"It is not a public document."
Token consultation!

Remaining Clear

What drives me,
Very powerfully as a mom is,

---

[51] Sandi is referring to a senior bureaucrat in the Special Education Department in the South Australia Education Department.

I worked in an institution,
I didn't last very long.
I don't ever want Cameron's eyes,
To look like the eyes of those kids.
When you look into children's eyes
That live in institutions,
They look hollow,
You just go into this world's darkness.
I want Cameron's eyes to have,
A sparkle of life in them.
I don't want Cameron,
To ever have that experience.
When I say I don't have the energy,
For this struggle any more,
I remember the eyes of those kids,
It propels me out of bed.
It makes me think about Cameron's future,
If I fail to have him included.

My Vision

I tuck my vision,
Into bed every night.
I tell him a good night story,
I close him into bed.

Every day he gets up,
Facing the world,
Overcoming incredible obstacles.
I can face that world.

Social Movement

When you look at other social movements,
The environment and feminist,
The first point is retelling the history.
We haven't done that.
We haven't actually gone and educated,
The wider community about the history of disability.
That really struck me,
When I went to a presentation,
On the history of disabilities.
It is so deep.
It goes back to ancient Greece,
Killing people with disabilities.

You look at the policies,
You see threads in every policy,
That is written about people with disabilities today.
It is not high in our consciousness.

I think until every child,
Learns how we have treated people with disabilities,
In the same way,
That we are starting to teach Australian children,
About aboriginal history,
We are stuck.

Private Pain/Public Trouble

I wrote a paper,
Private pain causes public trouble
I critiqued QPPD.
I wrote it very much as a social movement,
Women that care for kids with disabilities,
Got together in 1980.
They found their stories were really the same.
They decided that strength was,
Very much together,
Lobbying at a political level.
Some of the women that started it,
Are such gutsy people.

Inclusion: A Chocolate Easter Egg

I want you to most understand,
About inclusive education in Australia,
We are really good at talking words,
But we have no commitment to it.
It is a bit like an Easter egg.
The wrapping, writing and paper,
Beautiful and exotic,
Delicious appealing chocolate,
But when you bite into the egg,
There is nothing in the middle.
No substance.

Sandi and Valerie, looking back on the experience of forming these poetic transcriptions I found this writing to be transforming in my knowledge of who you are.

Sifting through your words was a profound and moving experience. I could see you, hear you, reflect on your experiences and my own, bringing my heart and intellect to the writing as I found a way to share my knowledge of your experiences. Your words were charged with energy as you shared your narratives. I hoped to capture that in the poetry.

I was nervous when I sent you the draft poems. I was worried my reduction of your words would make you feel I missed important parts of what you had to say and share. I worried you would question poetic writing as credible academic writing for university research. I was appreciative when you both responded to this part of the work with a sense of pleasure. I was thankful for the small changes you both offered that made some parts clearer. I felt a greater connection to you both through writing the poetic transcripts and I felt a sense of celebration when you responded to it. When you, Sandi, wrote, "I sit here rereading your work and I am blown away... Can I correct some names and the way I would like some words to be expressed? You are a very clever and talented woman, thank you for honouring our story. I am still overwhelmed, will collect my thoughts and get back to you" (E-mail, February 4, 2001). I was so relieved that I had done what I had hoped to do, honouring you in the re-presentation.

Valerie, in a conversation (May 2, 2001) on the phone I asked you to tell me what you felt when you read the poem. You said, when I told you in a letter my advisor thought your words were powerful, it was this comment that touched your heart. You were overwhelmed that someone you had never met, saw your story as powerful. That someone, in your eyes as educated and having higher status than you, was touched by your story was encouraging. Seeing your story written in a complete form empowered you and reinforced why you needed to continue to tell your story. This experience was what you needed to help energize you to tell and retell your story to help other parents.

In my next letters to you, I brought the themes within your stories forward, in an analytical description of your narrative accounts linking the literature that supports your words. I used direct quotations from the taped conversation transcripts to illustrate your ideas and thoughts.

In Chapter IV, I explored "What Counts as Knowledge? Whose Knowledge Counts?" in the research literature. In Chapter V, I explored how you came to know your knowledge as being constructed from your personal experiences, as mothers in relation to your sons, and how your knowledge is encountered on the professional knowledge landscape of schools. In Chapter VI, I looked at the school transitions you and your sons encountered and the threads of tension associated with this. In Chapter VII, I wrote about the gazes you encountered from others, in relation to securing inclusion for your sons. In Chapter VIII, I further explored your narrative in advocating for inclusive education for your sons. In Chapter IX, the final chapter, I write a reflective letter to you of how listening to your narratives and making meaning of its storied effect on my journey as an educator awakens in me my responsibilities to hold your stories dearly in my role as a school principal.

With Warm Regard,

Heather

CHAPTER IV

WHAT COUNTS AS KNOWLEDGE? WHOSE KNOWLEDGE COUNTS?

In hearing Valerie and Sandi's stories of securing inclusion for their sons I was struck by their struggles to have their knowledge recognized on the landscape of schools. Hearing these experiences provoked the questions, "what counts as knowledge?" and "whose knowledge counts?" on the landscape of schools. In this chapter I explore the literature related to these questions. In Chapter V, I explore Sandi and Valerie's narratives in relation to "What counts as knowledge? Whose knowledge counts?" on the school landscape.

WHAT COUNTS AS KNOWLEDGE?

What is Knowledge?

Jerome Bruner (1986) proposes that there are two basic ways of knowing the world: the paradigmatic or logical-scientific mode and the narrative mode. He argues that each mode provides "...distinctive ways of ordering experiences, of constructing reality" (p. 11). The paradigmatic concerns itself with logic, mathematics and various sciences that employ categorization, conceptualization and generalization as a way of knowing. In contrast, the narrative mode concerns itself with "...the vicissitude of human intentions" (p. 16).

Bruner (1991) states historically the study of the human mind was focused on how man achieved "true" knowledge of the world. Our understanding of how humans gathered knowledge and constructed reality was generated from studies on how people knew the natural or physical world rather than the human or symbolic world. This research focused on paradigmatic knowledge, which is the domain of logical-scientific reality constructed knowledge that is shaped by principles and procedures for establishing formal and empirical proof. Such research helped to understand how humans constructed and explained a world of nature in terms of cause, probability, space-time and so on but it did not give insight to how we constructed and represented human interaction.

Bruner argues that the narrative mode is concerned with the domain of human intention and that we organize our experiences and our memory of human happenings in the form of narrative. He maintains that the narrative mode is built upon the human condition. The use of narrative recounting, as a way of meaning making, provides the opportunity to view human experiences over time. Narrative recounting is a description of reality in terms of concrete human experiences, which gets closer to the multiplicity of meanings people attach to their lives.

Principles and procedures, just as in the paradigmatic mode, support the narrative mode of knowledge. These are based on how we organize experiences and our memory of human intention and action, which is mainly expressed in the form of narrative stories, excuses, myths, explanations for doing and not doing and so on. "Narrative is a conventional form, transmitted culturally and constrained by each individual's level of mastery and by his conglomerate of prosthetic devices, colleagues, and mentors" (Bruner, 1991, p. 4). Different from the knowledge constructed by logical and scientific procedures, which can be determined if it is right or wrong, narrative construction can only achieve "verisimilitude" making narratives a version of reality governed by convention and narrative necessity, not by empirical proof and logical requirements.

We know a great deal about the paradigmatic mode of thought. Throughout the centuries there have been many powerful ways, such as science, logic and mathematics, which helped us to carry on with the work of paradigmatic knowledge. "The imaginative application of the paradigmatic mode leads to good theories, tight analysis, logical proof, sound argument and empirical discovery guided by reasoned hypothesis" (Bruner, 1986, p. 13). These scientific procedures make formal connections in formal ways. With so much focus on the paradigmatic mode, Bruner (1991) questions why little effort went into discovering how humans construct the social world and the things that become known within it. He states the application of the narrative mode concerns itself with the vicissitude of human experience.

In exploring these basic ways of knowing Bruner (1986) contests that "efforts to reduce one mode to the other or to ignore one at the expense of the other inevitably fail to capture the rich diversity of thought" (p. 11). Paradigmatic and narrative thought have come to live side by side giving more reason to understand the narrative mode of knowledge construction. The narrative mode of knowing is equally important in understanding and viewing the world. It is narrative knowledge that authors, such as Connelly and Clandinin (1988), Johnson (1989), Sarbin (1986) and Belenky, Clinchy, Goldberger & Tarule (1986), concerned themselves with in their research. It is this work that I turn to now.

Narrative Knowledge

Sarbin (1986) suggests that human beings use narrative structures to think, perceive, imagine and make moral choices. He looks upon narrative as an organizing principle for human action. The narrative mode of thought facilitates the telling and interpreting of stories about interweaving lives. Stories are reflective of the way we think narratively in our everyday life. The use of narrative in everyday life is a way to help us put order in human affairs. MacIntyre (1981) illustrates how narrative is central to understanding human conduct:

> In successfully identifying and understanding what someone else is doing we always move towards placing a particular episode in the context of a set of narrative histories, histories both of the individuals concerned and of the settings in which they act and suffer. It is now becoming clear that we render the actions of others intelligible in this way because action itself has a basically historical character. It is because we all live out narratives in our lives and because we understand our own lives in terms of narratives that we live out that the form of narrative is appropriate for understanding the actions of others. Stories are lived before they are told – except in the case of fiction. (p. 197)

Narrative knowledge has a temporally structured form, which embodies past, present and future. Narrative knowledge has a forward/backward motion. The present is framed in our past and potentially envisioned future. The key to the structure of narrative knowledge is its narrative distinctiveness (Carr, 1986). Discussion about episodes across time is primarily narrative in structure (Gergen & Gergen, 1986). Many things are experienced retroactively and their significance is slowly clarified as we become aware of their role as we reconstruct our past, present and future in our narratives (Crites, 1986). The telling and retelling of experiences assumes a narrative form as we reflect on experiences. When told, our narrative knowing is being lived and lived in being told. Stories provide a means for interpreting and reinterpreting our experiences.

In their work in education, Connelly and Clandinin (1988) challenged the accepted view of knowledge as theoretical and as possessed by experts and the taken-for-granted meanings of the word knowledge as objective, conceptual, or found in books. In studying teacher knowledge, they claim that the paradigmatic notion of knowledge denies the experiential knowledge of teachers. They draw on Polanyi's (1958) theory of personal knowledge to explain teachers' personal and embodied meanings in educational situations. They see teacher knowledge as storied life compositions. These stories are narratives of experiences constructed from personal history and the social context in which teachers live out these stories. To understand this mode of teacher knowledge Connelly and Clandinin coined the phrase "personal practical knowledge" to allow them to talk about teachers as knowledgeable and knowing persons. They define this as being in:

> … the person's past experience, in the person's present mind and body, and in the person's future plans and action. Knowledge is not found only 'in the mind.' It is 'in the body.' And it is seen and found 'in our practices.' … When we ask 'what is personal practical knowledge?' for any one person, the answer is that it is a particular way of reconstructing the past and the intentions for the future to deal with the exigencies of a present situation. (p. 25)

Connelly and Clandinin help us to see that personal practical knowledge is knowledge gained from lived experience in all components of life. For teachers, practical knowledge is gained through experiencing the dynamic interaction of persons, things and processes in classrooms and schools. For Clandinin (1985) personal knowledge is "knowledge, which has arisen from circumstances, actions and undergoings which themselves have affective content for the person in question" (p. 362). Clandinin describes personal practical knowledge as "knowledge which is imbued with all experiences that make up a person's being. Its meaning is derived from, and understood in terms of, a person's experiential history, both professional and personal" (p. 362). It is more than knowledge of theory; it is knowledge evolving from experience, which enables teachers to make decisions about practice in the complex, dynamic and multifaceted components of schools.

Johnson (1989) disputes the traditional argument about what counts as knowledge. He rejects the dichotomy of "knowing how" and "knowing that." The classic view was that "knowing that" was far superior to "knowing how." Johnson refers to Dewey to argue for a view of knowledge as personal and practical. In further work by Lakoff and Johnson (1999) they contend that there is a crucial role for human embodiment in understanding reasoning and knowing and that classical psychology is wrong to believe that the faculty of reason is separate from and independent of bodily capacities such as perception and movement. They argue that human concepts and human reason are fundamentally embodied, being brain and body dependent. In their concept of "embodied knowledge" the body is the locus of interaction with the environment.

Belenky et al. (1986), in their research on how women know and view the world, grouped women's knowledge perspectives into five categories: silent knowledge, received knowledge, subjective knowledge, procedural knowledge and constructed knowledge. Silent women see external authority as holding the truth and being all-powerful. Women at the position of received knowledge and procedural knowledge see other voices and external truths as the primary source of knowledge. At these positions, a sense of self is connected to institutional roles and expectations and access to power comes from adhering to agreed-upon ways of knowing. The knowers have been taught a method and they use these rules to seek understanding. At the position of subjective knowledge women feel confident in their way of knowing, but this knowledge remains private for the individual lacks the skills to express herself and convince others. The fifth category is constructed knowledge. Constructed knowledge is connected to narrative knowledge. Constructed knowledge is formed intuitively, weaving strands of rational and emotive thought, with objective and subjective knowing, consequently moving knowing away from the taken-for-granted paradigmatic context that has dictated standards and methods for constructing knowledge and seen as a more valued way of knowing, to understanding that thinking and feeling are connected.

Bruner, Connelly and Clandinin, Belenky et al., Johnson and Sarbin's studies of knowledge put forth the notion knowledge is both paradigmatic and narrative. These authors collectively honour the worth and value of narrative knowledge along side paradigmatic knowledge. Knowledge is constructed across the whole spectrum and not just as the outcome of science and technology (Greene, 1995). Informed by the understanding of knowledge as both paradigmatic and narrative, I next explore professional knowledge, the professional knowledge landscape and parent knowledge to gain further understanding of knowledge on the school landscape.

Professional Knowledge

There is considerable theory and research related to the activities of teaching, enterprise of schooling and the development of paradigmatic professional knowledge (Day & Pennington, 1993; Eraut, 1994; Hargreaves, 1999; McNamara & Slingsby, 1993; Mercer, 1995; Russell, 1993; Williams, 1998). This research refers to professional knowledge that is "knowing that." This professional knowledge is the domain of logical-scientific reality constructed knowledge that is shaped by principles and procedures for establishing formal and empirical proof. Professional knowledge in this sense is based on theories and concepts, which are derived from bodies of systematic knowledge.

Eraut (1994) uses the term propositional knowledge to describe this body of systematic knowledge. For Eraut, propositional knowledge is comprised of systematic knowledge and is the traditional means by which syllabi in higher education are constructed. This systematized knowledge is often presented in a published format for the public. The applied use of this knowledge in professional activities is based on tried and true cases. It is this knowledge that usually counts for professional knowledge, knowledge that is grounded in paradigmatic knowledge.

The growth of professional groups asserting expert knowledge in respect to students' needs is an increasing occurrence. Paradigmatic knowledge is a crucial component in contributing to the identification of professional knowledge and is used in order to establish or negotiate a particular definition of professionals' skills based on a body of systematic knowledge. The development of paradigmatic knowledge based on a theoretical perspective, within the culture of professionalism, creates and maintains professional authority. Armstrong (1995) contends that the development of the culture of professionalism has led to the specialized training and language characteristic of each professional group. This specialization contributes to the separation between professionals and their clients.

Professional Knowledge Landscape

In their studies of teachers' "personal practical knowledge," Clandinin and Connelly (1995) realized they needed a way to both conceptualize their research-based understanding of this knowledge and a way to represent the complexity of the contexts in which teachers compose this knowledge and experience it in practice. They developed a metaphor of a professional knowledge landscape to represent these complexities.

> A landscape metaphor is particularly well suited to our purpose. It allows us to talk about space, place, and time. Furthermore, it has a sense of expansiveness and the possibility of being filled with diverse people, things, and events in different relationships. Understanding professional knowledge as comprising a landscape calls for a notion of professional knowledge as composed of a wide variety of components and influenced by a wide variety of people, places, and things. Because we see professional knowledge landscape as composed of relationships among people, places, and things, we see it as both an intellectual and a moral landscape. (pp. 4-5)

Clandinin and Connelly see the professional knowledge landscape as a complex matrix of historical, personal, communal and professional knowledge, which is influenced by a wide variety of people, places and things. It is understood in terms of personal and social narratives of experiences woven together, which have a storied influence over one and another. Narratives of personal and social experiences of everyday life, personal history and social history on and off the school landscape contribute to teachers' personal practical knowledge. Individuals draw upon their histories on the communal and professional landscape, are influenced by their position on the professional knowledge landscape, and lace these histories with their personal life off the school landscape. Conceptualizing the professional knowledge landscape as both an intellectual and moral landscape Clandinin and Connelly see personal practical knowledge as professional knowledge; it is what teachers know.

The professional knowledge landscape has two fundamentally different places in which teachers live. One location is behind the classroom door with students and the other is outside the classroom in professional communal spaces, which they share with others. The in-classroom place is the context for narrative knowledge. Here teachers author their own knowledge living in a relational space with their students. Here teachers are characters in their own stories of practice and feel they have autonomy, a sense of ownership. As characters in their own stories of teaching, teachers are generally freer to practice and create curriculum within the limits of the program of studies.

The privacy of the in-classroom place creates an environment, on the professional knowledge landscape, that is seen as a safe place for teachers where teachers are for the most part, free to live out stories of practice without scrutiny. Clandinin and Connelly (1995) say these lived stories of practice in classrooms are essentially secret stories. Teachers have few out-of-classroom places where they can share these stories of practice. Teachers need places to tell and retell these stories of teaching to have the possibility for awakenings and transformations of their practice. "Teachers need others in order to engage in conversation where stories can be told, reflected back, heard in different ways, retold, and relived in new ways in the safety and secrecy of the classroom" (Clandinin & Connelly, 1995, p. 13). To awaken to the possibilities and relive new ways of practice these conversations need to happen outside the classroom. However, the out-of-classroom place on the professional knowledge landscape is a significantly different epistemological and moral place, usually not a safe place to share secret stories of teaching.

The out-of-classroom place on the professional knowledge landscape embodies expert paradigmatic knowledge. It is in this space that teachers encounter outside experts and "authority" in the form of policy and research. Knowledge in the out-of-classroom place arrives formulated in textbooks, pamphlets, workshops, staff meetings, information sessions, newsletter, e-mails and the like. This is a place on the landscape filled with an abstract rhetoric of conclusions (Schwab, 1962). Teachers are engaged in abstract talk about abstract policies and prescriptions. They are required to articulate their knowledge of policies and administrative practices and other recognized forms of "authority."

Clandinin and Connelly (1995) say that "the out-of-classroom place on the professional knowledge landscape, structured as it is by the sacred theory-practice story[52], is not a place where basic human desires, and the reflective relational stories they engender, are nurtured" (p. 157). In this space teachers often live a cover story as expert people discussing research findings and policy directions. Talk in the out-of-classroom place on the professional landscape is increasingly abstract as the participants try to make sense of the already abstract material of policy and research that is far from the teachers' knowledge lived out in the classroom. This is not a space that allows teachers to talk about what matters to them, the stories of children and the classroom events, for they must remain as characters that are certain, expert people.

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[52] For Clandinin and Connelly (1995) the sacred theory-practice story is constructed from the taken-for-granted belief that theory is superior to practice. A sacred story is a story that is difficult to articulate because the story lies deep within the individual's consciousness. The taken-for-granted notion of theory-driven practice on the school landscape makes it difficult to hear different views of knowing and because it is so powerfully positioned within the consciousness of educators it is difficult to change the story.

What is Parent Knowledge?

In her research, McKiel (1996) explored parents' experiences of caring for their hospitalized children. McKiel, a nurse practitioner and educator, questioned the taken-for-granted invisible boundaries imposed on the knowledge parents could and should bring to the care of their children while in the hospital. In this work she came to understand that parents came with knowledge about their children that was personal to them, that they had acquired through their experiences of knowing their children and were experiences the nursing staff did not have. The parents had connected knowledge. Individuals with connected knowledge learn to use themselves as instruments of understanding, weaving their passion and intellectual lives into recognizable wholes. Through listening to parent stories, McKiel began to understand that parents had connected knowledge and wanted to have input in their children's health plan based on their knowledge of their children. They also wanted information that could become part of their personal practical knowledge to enable them to influence their children's health care. In her conclusion, she saw that the present parent/nurse relationship was one where parents could make suggestions but were essentially members of the team without voting privileges. She questioned "what constitutes professional knowledge and whether there can be boundaries erected around a body of knowledge so that it is designated to 'belong' to a specific discipline?" (p. 184). She also asked is this knowledge something parents could learn and use to improve their children's health.

Pushor (2001) in her research of parents' positioning on the landscapes of schools points out that similar research to Clandinin and Connelly's (1994, 1995, 1998) on teachers' personal practical knowledge has yet to be done with parents in relation to their children's formal schooling. Pushor presents the idea that parents too have personal practical knowledge.

> Parents have practical knowledge gained from living in contextualized situations – their homes – with persons, things and processes – their children, other family members, possibly a pet, toys, books, games, sports equipment – all interacting in dynamic and complex ways – the juggling of homework, sports activities, meals, laundry, bedtime routines, a family outing, a birthday celebration. Practical parent knowledge is knowledge gained from living with children in complex and ever-changing situations, although it may be informed by knowledge drawn from books on parenting, on stages of development or childhood illnesses. (p. 230)

McKiel (1996) and Pushor's (2001) reference to parent personal practical knowledge is interesting as I reflected on Valerie and Sandi's stories. Although this was not a study of parents' knowledge, their knowledge of what was best for their sons appeared to be expressions of their "personal practical knowledge."

Webb's (1995) question, "what counts for teacher knowledge?" McKiel (1996) and Pushor's (2001) work on parent personal practical knowledge and Clandinin and Connelly's (1994, 1995, 1998) work on teachers' personal practical knowledge and the value it plays in understanding teachers' practice contributed to my questions. I wonder about parents' personal practical knowledge and the value it has on the school landscape. In the next section I will explore the literature on "whose knowledge counts?" on the landscape of schools.

WHOSE KNOWLEDGE COUNTS?

The Western education system has been built on an assumption of different skills of parents and teachers (David, Edwards, Hughes & Ribbens, 1993). Formalized education was created on the assumption of the need for professional educators to teach children. Mothers play the role of being available to support their children's transition to school and being involved in their children's schooling as determined by school personnel. Formal education systems were built on the assumption of different roles for parents and educators in children's schooling. David (1993) states, "it has become commonplace to discuss this form of education system by talking about 'the school gate' as the symbolic boundary between home and school" (p. 38). Mothers have an active role in the early development of their children, at the beginning and end of the school day and during school holidays but their responsibility ends magically at the 'school gate' when teachers take over this responsibility. A legal term – in loco parentis – meaning in place of parents, has been used to describe the duties of teachers on the school landscape. The intention of formal schooling was not to see educators as an alternative to parents but rather "to provide skills that the majority of parents could not – either in terms of time or ability – provide their children. The 'school gate' symbolized that distinction between home and school, family and formal education" (David, 1993, p. 39).

Ribbens (1993) suggests that the existing policies in Western industrial societies generally focus parental involvement on the choice of school their children will attend while not extending parental choice to aspects concerning their children's experiences within the school system. Sarason (1995) sees the barrier to parental involvement in school decision-making as "a form of rigid boundaries professionals erect to ensure that 'outsiders' (who may be other kinds of professionals) remain outsiders" (p. 7). The boundaries of who is in and who is out are in place to define and protect the power, authority and decision-making devised from formal training and experience of the educators on the professional knowledge landscape. On the school landscape the dominant knowledge authoring placement and education decisions for students with disabilities is constructed from the paradigmatic mode.

For Sarason, a further effective barrier that exists between meaningful school and parent involvement is the way we define assets and deficits on the professional knowledge landscape. This is a rigid boundary between parent and school that prevents professionals and parents from exploring the knowledge each brings to the dialogue. The landscape of today's schools is reflective of an attitude that parents are to be given the opportunity to give their input but this in no way means that this input would, or should, shape the practices of the professionals on the school landscape (Gartner, 1988). McEwan (1998) points out educators often fail to give parents credit for understanding their children. "Parents would like to have their personal knowledge and understanding of their children validated; they get angry when educators assume that the experts know best" (p. 12).

The next chapter is the first of the four letters written to my research participants of the interpretative representation of their personal narratives. In this letter I will explore Sandi and Valerie's "parent personal practical knowledge" and how this knowledge counts or does not count on the school landscape as it relates to their experiences.

CHAPTER V

WHAT COUNTS AS KNOWLEDGE? WHOSE KNOWLEDGE COUNTS?

THREADS OF TENSION

Parents' Personal Practical Knowledge

Dear Sandi and Valerie,

Your knowledge, in relation to your sons, comes from your personal experiences as mothers. You both tell your stories as a means of making sense of your lives with your children. You live out these stories in your relationships with your sons as mothers. Your knowledge, as mothers, is narrative, embodied, relational knowledge. Your knowledge about your sons is constructed socially, practically and experientially oriented to situations and shaped by your purposes and values. Your knowledge is constructed on the landscape of home and community, where you lived parenting stories rich with history, everyday routines and expectations. Sandi, when you told me "my thinking about how Cameron can be included is different than teachers' because I am used to including Cameron in our life everyday. It is such a natural part of life for me" (Conversation, October 31, 2001) highlighted how your knowledge of including your son was constructed through your personal experiences with him.

Valerie, you brought to the school your experiential knowledge. Your knowledge was embodied and enacted in your life. It was knowledge that came out of being Jason's mother and you expressed your knowledge in the situations where you were Jason's advocate. Valerie, you valued your personal knowledge, as Jason's mother, to help you make meaning of what others should do in response to your son. For you, it was often difficult to have your knowledge of your son be understood by others. You illustrated this when you said "it takes so much energy to educate people to treat him like a person and see past what they think they see. To see who he really is" (Conversation, May 22, 2000). However, in these situations you did not see yourself as a simple conduit for receiving knowledge from the professionals nor needing to rely on their knowledge for decisions about your son. The rhetoric of conclusions dispensed by professionals and the school personnel did not stop you from rejecting the taken-for-granted notion that children with disabilities had limited opportunities and should go to segregated classes.

Sandi, your knowledge of your son, while also based on your narrative knowledge as his mother, was further developed through educating yourself about inclusive education. In addition to embodying your narrative and relational knowledge you sought to educate yourself, to have your personal practical knowledge shaped by paradigmatic knowledge. As you said, " I worked really hard filling up the tank of knowledge" (Conversation, October 31, 2000). You recognized you needed to construct and reconstruct your own knowledge in relation to paradigmatic knowledge to combat the story of parent as recipient of others' knowledge on the professional knowledge landscape. You developed your technical vocabulary to use with school authorities. You read extensively to understand curriculum and adaptation. You actively participated in parent education sessions, professional education seminars and professional committees, which helped shape your knowledge about the structure of schools and the implementation of inclusive education.

Whose Knowledge Counts? The Professional Knowledge Landscape

Sandi and Valerie, in going from home to school, you both encountered teachers and other professionals on the out-of-classroom places on the professional knowledge landscape. Entering schools Valerie, you were unaware that the out-of-classroom places on the professional knowledge landscape embodied expert paradigmatic knowledge. On these places on the storied landscape, teachers and other professionals were required to portray themselves as characters who are certain, expert people. Parents are expected to respond to the knowledge of the professionals as receivers of that knowledge. On out-of-classroom places knowledge is viewed as received, expert and hierarchical.

Sandi and Valerie, you both encountered stories on the professional knowledge landscape that competed with your knowledge of your sons. You were expected to accept the rhetoric of conclusions dispensed by professionals that determined, in abstract policies and prescriptions, specified ways in which your children with disabilities were to be treated. Bumping up against the story of segregated education, embedded within the professional knowledge landscape, gave rise to your difficulty of establishing and maintaining a new story of inclusion. In the out-of-classroom places, professionals worked to strip you of your voice and agency for your children and worked to morally wear you down. Sandi, you experienced how professionals did this when you described your encounters with the Education Department's Guidance Officer.

> This Guidance Officer that had been part of the ascertainment process (student placement) over the two years had rung me many times up at home after hours. She spent hours on the phone trying to talk to me about Cameron being included as not a viable option. (Conversation, October 31, 2000)

Valerie, you had similar experiences with professionals, such as the time Jason was assessed to determine his disability. In response to the doctor's inquiry of what you saw Jason's potential to be, you said:

> I want him to reach the complete potential that he can. I want him to be an adult in a world of adults, I want him to be and do whatever he can possibly do to be there to be successful. (Conversation, June, 2000)

The doctor looked at you and said, "I don't know about being a successful adult. I don't know" (Conversation, June 5, 2000). You felt the doctor was insinuating that your expectations were too high. Mickelson (2000) describes experiential knowledge such as "(m)others' knowledge, in contrast, carrying with it the socially constructed overlay of sentimentality and sacrifice ascribed to motherhood, is heard 'en passant,' often listened to through a filter of prejudgments by half-blocked ears" (p. 104). Valerie, you were viewed through the professional lens as not possessing the paradigmatic knowledge of formal training. Your knowledge was personal practical knowledge as Jason's mother and did not have credibility on the professional knowledge landscape.

Sandi, although you were equipped to participate in conversations on the out-of-classroom places on the professional knowledge landscape, you discovered that, by being parent/other, you were still not perceived as qualified to make decisions about your son's education. Your knowledge still carried the notion of 'lay' person and it did not matter how much you developed your expert paradigmatic knowledge. You were still branded 'parent.'

Valerie and Sandi, you had a deep sense that your parent personal practical knowledge of your sons' needs had no place in the discourse on the out-of-classroom places on the professional knowledge landscape. Your parent personal practical knowledge was not valued nor acknowledged. The rhetoric of conclusions ignored, denied and devalued your personal practical knowledge of your children composed in the contexts of your homes and your everyday lives. On the out-of-classroom places on the professional knowledge landscape teachers and others talked an abstract language of results and policies you were expected to accept. You were to learn that this was not a space that allowed parents to talk about what mattered to them, the stories of their children, for you were expected to remain as characters who received the paradigmatic professional knowledge. As parents of children with disabilities you began to understand that your lived stories were different from the ones the professionals constructed for your sons.

Valerie and Sandi, you did not grant the school personnel full control. As parents, you would not relinquish your parental right to be involved in educational decisions for your sons and would not hand over the responsibility to the professionals. Your actions negated the notion that school personnel had professional autonomy in placement and academic matters related to your children's education. You worked to change your children's school experiences. You saw yourselves as playing an active role in your children's education and wished to be able to supplement, oversee and monitor your children's school experiences. You both experienced being placed outside the boundaries of the dominant narrative on school landscapes that credit professional paradigmatic knowledge. However, implicitly and explicitly, you both presented yourselves as equal to the professionals and teachers. You worked against the storied plotline because your parents' personal practical knowledge was what you valued. With this at the heart of your knowing you both continually sought to have your knowledge count on school landscapes.

Whose Knowledge Counts? Assessment

Sandi and Valerie, you both experienced expert professional diagnosis as related to your sons' disabilities. Once the assessment procedure was initiated, both of you encountered incidences where professionals attempted to marginalize you in the process. Your experiences made me wonder if the process of assessment limits parent voice and actions in relation to the outcome. In the assessment process you both worked to be on equal terms with the professionals. You wanted the assessment process linked to the uniqueness of your child, not formulated on conclusions based on policy guidelines, which predetermine what a child with a disability will have access to.

Sandi, you encountered the process of assessment when Cameron began attending preschool. Being part of the formal education system brought with it what was called the 'ascertainment process.' This process is initiated when a student with a disability may require specialized educational services and support within the education system. The purpose of this process is to make recommendations and ultimately decide the level of programming and specialist support a student needs so that the Education Department can request adequate financial resources from State Treasury. Members of the ascertainment process team included you, teachers and professionals from the Education Department (Hamilton, 1997).

> All the policies say ascertainment is about helping schools understand what they need for children. What actually ascertainment is is government telling parents what they are allowed to have for their sons and daughters for education in practice. (Conversation, October 31, 2000)

Sandi, you strongly critiqued the stated purpose of the ascertainment process. Although the process gave an appearance of working to identify educational needs of children, you saw the purpose as primarily a process to allocate resources. To you, the process was about professionals seeking to maintain control over the distribution of resources and securing the autonomy of their professional roles. There was nothing about the uniqueness of your child in the dialogue of the assessment. As you said, "Guidance Officers are tollgate keepers of the system who have rules that you are to follow" (Conversation, November 6, 2000).

The meetings to report Cameron's results on informal observations and formal tests that were part of the ascertainment process, transpired on the out-of-classroom place on the professional knowledge landscape. Talk at the meetings was about abstract assessments that were conducted to display Cameron's deficits with the purpose to limit the choices you would be granted as to where he would start Grade 1.

> Two years of meetings with them (professionals) finding the deficits in your child then telling you back the deficits in your child. It is really confronting. Most parents give up after the first two or three meetings. They are set up to do just that; the system structures them exactly that way. It is only really stubborn nuts like me that go on to fight it. (Conversation, October 31, 2000)

You discovered that the purpose of the ongoing meetings, which occurred every month, was to discuss the knowledge the expert professionals had constructed about your son. To you, the professionals were relentless in their efforts to describe his deficits. These meetings were not about your parent personal practical knowledge of Cameron. Your vision of what Cameron's life would look like had no place in the discussions on the out-of-classroom place on the professional knowledge landscape that detailed their cumulated list of Cameron's deficits that would determine where he would go for Grade 1. You were denied the opportunity to make a genuine contribution in cooperation with the professionals in determining what would best meet his needs. You were expected to be the recipient of the expert professional knowledge and to pursue the set goals, defined by professionals, for your child.

As part of the process, the Guidance Officer assigned to your case requested that Cameron have an IQ assessment. You were not willing to allow the Education Department to administer the test.

> I wouldn't let the education department do it. If an IQ test was going to be done then it would be done by one of my friends (who was a psychologist). So we wrote the report and it was really supportive of inclusion and they were really cross because it was not what they wanted. (Conversation, October 31, 2000)

You were worried that the segregated provision embedded in the ascertainment process would place structural constraints on the Education Department's psychologist's response as to where Cameron would attend school. The use of IQ scores and categorization was deeply embedded in the assessment process and reporting done by the psychologists within the ascertainment process. To avoid this you sought a professional that would not have to work within these professional constraints. You wanted a process in place that could explore who Cameron was outside the prescribed purpose that you saw inherent in the process, which was to limit your choices.

In response to your psychologist's report, the Education Department worked to help you understand Cameron still could not be included. You shared, "the Guidance

Officer spent a whole heap of time telling me that Cameron's IQ wasn't high enough to go into a regular school" (Conversation, October 31, 2000). You encountered a conflicting story when the assessment you had completed by a psychologist outside the institutional landscape said how Cameron could be included and when your fears were reinforced when the Guidance Officers used only the IQ score to confirm their belief Cameron could not be included. Although the purpose of the ascertainment process was to determine a placement decision, underlying the decision-making process was an imposed limitation as to where the placement could occur. Swann (1987) states as long as "… there remain segregated special schools, placement will remain the crucial decision in assessment, and assessment must be predominately a selection mechanism" (p. 193). The professionals relentlessly worked to wear you down to attempt to get you to eventually accept a segregated option for Cameron.

> What they do is re-ascertain children every two years. If they don't get you out the first year (regular education) they keep at it, wearing you down until you finally agree. (Conversation, November 6, 2000)

Sandi, you refused to accept segregation for Cameron and you came to realize any victory was to be short lived because there would be future rounds.

When you moved, the state you settled in did not have an official ascertainment process. However, you were to encounter further requests for Cameron to be assessed. Cameron's classroom teacher asked for a psychological assessment to be completed. You gave permission although you felt "the testing is the gate keeping process" (Conversation, November 17, 2000). The assessment process in this state was different from what you experienced in the ascertainment process in some ways but still had the same outcome.

You were again forced to endure long conversations with professionals. They saw it as their responsibility to help you understand why your request for Cameron to continue to be included was not a rational choice.

> Two years ago I had this huge two hour conversation with Cameron's Guidance Officer. They are psychologists in South Australia. So they are probably better trained about segregation. She spent hours telling me that Cameron needed to be with people like him. I said, "Tell me what people like Cameron are. Are they boys?" She said, "No Sandi, we need to have this conversation. No, it is like, my husband's secretary is a really nice person. I really like her but she is not part of my network because we are different." I said, "That is really interesting because people in my network are straight, gay, black, white, young, old, disabled, not disabled. They are the spectrum of people. So Cameron gets exposed to a lot of people that are different all the time in lots of different places and lots of different ways." I said, "You told me more about your social status than what it actually says about Cameron." (Conversation, November 17, 2000)

You experienced, as Armstrong (1995) describes, "(w)hatever the interests of the child, the interests of professionals would inevitably become tied to their ability to negotiate definitions of children's needs in terms of their own professional models" (p. 144). He says that this dominance of the professional perspective creates an unequal opportunity for parents to contribute in the assessment. The assessment process is part of the bureaucratic management narrative, which is in place not to serve the needs of the child but the institution's narrative. The purpose of the assessment continued to be about Cameron being placed in a segregated classroom.

> They spent the first meeting saying Cameron needed to go to a speech and language class, which is a segregated class for kids without language at another school. They do the testing. They direct you to a special school. They (psychologists) see very much that their role is to maintain the divide. (Conversation, November 17, 2000)

Your reason for refusing to allow the Education Department's psychologist in the previous state you lived in test Cameron was reinforced when you allowed this psychologist to assess Cameron. This psychologist's response to Cameron's educational needs came from two sources. First the psychologist resides upon the professional knowledge landscape of the institution and therefore must adhere to the agreed upon process for assessing and recommending resource allocations. She lives on the plotline of the institutional narrative, which places pressure on the professional to make recommendations within the pressurized budget restraints and allocated placement options. Second, the psychologist had a personal interest in the outcome of the assessment. This was reflected in her personal values about children with disabilities. She scripted Cameron as 'other.' She adapted her strategies in pursuit of objectives in relation to her interest to maintain the status quo of who should attend a regular classroom and who should be sent to a segregated classroom.

For you Valerie, from the time Jason was diagnosed as having autism you were not submissive to the commands of authority and did not see yourself as powerless. You questioned privileged professional knowledge and demanded that your personal practical knowledge of your son be considered.

> I remember being so disgusted with the psychologist. I found out later when the report came that it was a psychology assistant, whatever that meant. She started testing him at his age level instead of working up from simple fun things to more challenging things so he was failing right off the bat with some of the stuff she was doing. I remember discussing this with her. She tried to put me into my place like. 'I am the professional here.' I just told her, "You don't know what you are doing. You are setting him up for failure and now he won't even be able to do the little things." She was aghast. He was reacting to his frustration. He was just hollering. She asked about medication. I said, "He is not on medication and he has never been on medication." She was shocked. I said, "This behaviour has nothing to do with needing medication, it has everything to with what you are doing with him and how you are doing it." (Conversation, June 5, 2000)

You were denied the opportunity to make a genuine contribution, in cooperation with the professional, to understand Jason's abilities and the circumstances in which they were being assessed. Ultimately this led you to challenge the way the professionals conducted the assessment. You felt strongly about the situation and expressed this without concern.

> The same day an hour or so later I meet with the doctor. Now this doctor I think she wasn't a psychologist. She was just a paediatrician maybe. I am not sure. I remember her sitting there asking me about Jason's future. I mean this kid is five years old. Asking what do I want for him. I remember saying to her I can't remember the words exactly. I am trying to remember what I said something like, "I want him to reach the complete potential that he can. I want him to be an adult

> in a world of adults; I want him to be and do whatever he can possibly do to be there and to be successful there." She looked at me and said something like, "I don't know about being a successful adult." She was insinuating that my expectations were way too high. (Conversation, June 5, 2000)

Valerie, you were unaware that parental involvement in decision-making for their children is often limited to identifying those aspects of the child's behaviour that fit or do not fit with the knowledge of the professional. Parents are marginalized in the process (Armstrong & Galloway, 1992), not because professionals exclude them but because they are denied the opportunity to influence how ability is conceptualized. Armstrong and Galloway argue the disempowerment of parents arises from professionals seeking to secure the autonomy of their professional role. You experienced the boundaries professionals erect as to 'who is in' and 'who is out.' These boundaries are erected as professionals work to define and protect their power, authority, and decision-making devised from their formal training (Armstrong, 1995) and experiences as professionals on the professional knowledge landscape.

> I didn't say anything. I can't remember what I said to her but I remember leaving there in tears all the way home. Just being a mess. One of the few times that Kevin (Jason's father) said the right thing about Jason and the way I am with him. He said, "You just never mind. You just forget that this day ever happened. You believe what you believe and never mind what she said." That stuck with me all these years. I have never forgotten it because it was one of the few times that the support was totally there. That was pretty awesome. So I did. I just negated that part of it for my focus for Jason. I just ignored all of that. As just being a bad

> experience and just someone who didn't know what they were doing and didn't care enough to see beyond things, to see beyond what they could see.
>
> (Conversation, June 5, 2000)

Valerie, the assessment process did not enhance your role in the decision-making for Jason's future goals. Rather it restricted you by challenging your expectations for Jason when you were told you should be satisfied with limited prospects for his future. You saw assets in Jason as you storied your narrative as his mother and advocate. The helping professionals were "deficit oriented" in their conception of Jason's abilities. This limiting view did not sit well with you. Having identified and pursued sources of strength outside the assessment process you decided that you should rely on your personal practical knowledge to guide you in your vision for Jason and not allow the privileged professional knowledge to effect your vision.

Valerie, you did not see yourself as just a parent who should receive others' knowledge. You saw yourself as someone whose personal practical knowledge was important in determining the formal education of your child. The professionals viewed you, as a parent, as unequal in status, power and knowledge. Your knowledge was narrative knowledge. You found meaning in your relationship with your son as you advocated for him and you were confident in your ability to learn from your experiences while tempering your learning with the words of others. Your knowledge was not that of a silent woman, feeling passive and dependent while seeing authority as all-powerful. You saw possibilities for your own moral decision-making based on your construction of knowledge of your son rather than acting as an agent of received knowledge. Your story is one of questioning and challenging expertise and the negotiation of shared construction of knowledge about your son's abilities.

Whose Knowledge Counts? In the Care of Others

Valerie, your story speaks of your need to know what happened for your son when he was placed in the care of others. Your first encounter with others being responsible for Jason's care began when he attended the local daycare full-time as part of the early intervention he received in his community.

> I remember going to the Director and telling her I want to know what you do with him from the time he comes. The daily routine changes. I didn't want to be picky about it but I need to know what you are doing. I need to know why he is here and the purpose. I know my perspective on why he is here but I want to know your perspective. I want to know what you are doing with him to help him grow and if they didn't tell me I would ask why. (Conversation, May 22, 2000)

You were conscious of the inequity embedded in the parent/professional relationship on the professional knowledge landscape but did not see your questioning as compromising professional integrity. Questioning for you was necessary if you were to be assured that Jason was in the best learning environment possible.

> The first monthly meeting I went to I was asked why was I there? I said, "This meeting is about my son. I want to know what you are saying about him. I want to know what you are doing to help him mature and learn. How you are teaching him things and you need to know how I am teaching him things at home so that we are teaching him the same ways because we need to generalize." I didn't use those exact words but we needed to work together to have the same focus in how

> we carried out the same goals and how I carried out those goals. (Conversation, May 22, 2000)

Valerie, you saw yourself as an active participant in shaping your child's education plan. You did not see yourself off the storied landscape of the daycare. Nor did you see your stories of teaching Jason at home as being composed and lived on the edge of those being composed by the daycare staff. You saw the need for Jason's learning, on and off the daycare landscape, to be storied as one plotline, not two separate plotlines. You worked to bring the two worlds together. It was important to you that you were permitted to travel between the two worlds as an equal partner.

> They were stunned literally. Their eyes got big. Their mouths kind of, you know. I sat and waited. They really struggled with that until they realized that no parent had expected that from them before. That shocked me. I was stunned when I heard that. I was like what do you mean? No parent wants to know? I realized that a lot of them didn't have the courage. (Conversation, May 22, 2000)

Valerie, you demanded a position on the out-of-classroom landscape on the professional knowledge landscape of the daycare as the staff made decisions for Jason's learning. In making this request you discovered that parents were not expected to question how the staff taught nor were parents seen as members of the planning team. The plotline was one in which power and authority rested with the daycare staff and parents were subjects of the system. Hierarchical relationships on the daycare landscape were defined and understood as to who is in and who is out on the professional knowledge landscape. You began to examine the factors that limited and inhibited the participation of parents in the discussion of their children's learning at the daycare. The boundaries of responsibility, which the daycare staff viewed to be theirs and not an "outsiders," were threatened by your insistence on being part of the monthly program planning meetings.

> I started questioning. I am so grateful that I had the courage. That had to be God given and the wisdom to know. I didn't know I was doing the right thing. I didn't know it was so right for Jason. They slowly accepted me. They didn't have a choice and it didn't bother me that they didn't want me there. They didn't make me feel uncomfortable although I don't know if at that stage of the game I would have cared. I wasn't going to be uncomfortable. That was my mindset. They could do whatever they wanted but I wasn't going to be uncomfortable there. I was in charge. I was not going to let them control my child. They were not going to be completely responsible for him because I needed to know. I would not let them rule his life. (Conversation, May 22, 2000)

Valerie, your strategy to obtain partnership in negotiating Jason's education at the daycare with the professionals led to shifting the power balance embedded in the professional role. You did not allow the professional role to create a subordinate role for you as a parent because you had a deep sense of your parent personal practical knowledge. You disputed the story prescribed for you as parent of a child with a disability as someone who should view knowledge as received, expert and hierarchical.

> The meetings progressed. It was quite wonderful. He was at the daycare for three years and by the fourth year the Director of the daycare asked me to come in. She asked me how she could get other parents involved with their kids. (Conversation, May 22, 2000)

The outcome of your persistence was that the Director of the daycare saw you as a source of information and knowledge in helping the daycare staff engage other parents in the planning of their children's education. You were no longer trapped in the traditional plotline scripted for parents and the daycare Director awakened to the possibilities of learning by welcoming parents.

Whose Knowledge Counts? Restorying the Boundary of Collaboration

Valerie, while Jason attended the daycare you became aware of the relationship the daycare had with the school district in securing Program Unit Grants (PUG), a government granting system, at the time, used to fund the education of children with disabilities in the pre-school years. Although Jason attended the daycare it was the School Board that applied for the grant and oversaw the administration of the grant.

> I didn't have a clue who this woman was (Sharon, the school district's special needs coordinator). I didn't have a clue why she was even there (an education planning meeting at the daycare). I was told she was from the school through the grant system. She was the one who okayed all the grants and stuff. She had all these great ideas. I expected her to explain them to me in a way that I could understand. That was difficult for her. No other parent had ever questioned or asked these things. (Conversation, May 22, 2000)

Valerie, in your first interaction with Sharon you were to learn the story of parent and professionals working collaboratively, in the way you worked to establish it at the daycare, was to be drastically altered. There were negative consequences to this change when School Board personnel joined the daycare landscape.

> Before the case conference to plan Jason's last year at daycare I told Sharon on the phone I wanted a swim program for him. I knew he loved water and it would be with other kids. Sharon made it very clear on the phone she wasn't going to give that to me. Sharon admitted that money was not the issue. It would cost $60. She said, "Swimming would not be useful." By then I knew about autism. Jason had just been diagnosed. I said to her, "You don't understand autism. Maybe you need to read a little bit about autism before you say this to me because you have no idea how this could possibly help him down the road." When money wasn't the issue why was it such a big deal? I didn't get it. There again it was a control thing. She wanted to be able to say yes or no and because I was pushy or I expected it, it was no. That is where the personality clashes started. (Conversation, May 22, 2000)

When Sharon joined the daycare professional knowledge landscape your hard earned acceptance as a contributing member in determining what Jason's education program should look like changed. Your parent personal practical knowledge began to be disputed. Whose knowledge counted began to shift to the knowledge of the expert professional with the inclusion of Sharon, the School Board personnel, taking a seat at the daycare landscape. The gate, opened by the daycare staff to the possibility of giving voting privileges to parents, was now being closed. Your narrative knowledge, embodied personally and socially, was no longer valid. You encountered trouble as you tried to retain your place in a collaborative story.

> I realized I needed to do some pushing here for this (swimming program). So that is why I phoned the consultants. I wasn't going to accept this. Especially when she

> said money wasn't an issue. I thought this is Sharon's problem. She was going to deprive Jason of something that might be very important to him because she had said no to me on the phone. She is a professional and nobody questions that. I phoned two consultants from the city. They were very supportive of the idea of the swim program. (Conversation, May 22, 2000)

To maintain your position at the table, deciding what was best for Jason, you sought help from other professionals to support your claims. The professional knowledge landscape on the out-of-classroom place of the daycare now embodied expert paradigmatic knowledge. Your story moved away from authoring Jason's educational program to disputing who had the authority to author the story.

> At the case conference Sharon said, "Valerie wants a swim program for Jason. I am not convinced that this is necessary." She looked to the consultants and said, "I would like your input." The speech consultant supported a swim program. Then Sharon asked the education/behaviour consultant. She said, "These kind of programs are essential for kids like Jason." Sharon looked at her and said, "Beneficial you mean, not essential?" Those were her exact words. The consultant looked at Sharon and said, "They are critical for kids like Jason." What could Sharon say? She flipped her paper over and started writing. Then she looked up and said, "I will authorize the swim program but I will not authorize the aide to be there." (Conversation, May 22, 2000)

Valerie, you challenged Sharon's refusal to support your request by countering her argument with the authority of the consultants' expert paradigmatic knowledge. You asserted your personal practical knowledge of the importance of a swim program for

Jason through the authority of other professionals. The process of deciding, from Sharon's point of view, was not to be participatory with parents. Sharon could not dispute the consultants' expert paradigmatic knowledge because she herself viewed knowledge as received, expert and hierarchical. Sharon had to agree because you would not live your part in the prescribed story – parents receive knowledge. Sharon was forced to approve a swim program for Jason. However, she was not going to make this approval work with ease. She denied Jason access to the program aide to support him in this part of his weekly learning activities.

> I was crying because I knew she could not deny Jason the swim program. Everybody heard what the consultants said. She could not say no. I said to her, "The aide is paid a day rate so why shouldn't she be there?" Sharon said we would have to meet and discuss it. So I got up and left the meeting. I phoned her office and set a meeting time. I came back into the meeting room and said, "We are meeting at two o'clock tomorrow." I sat back down. I felt the vibes from the daycare Director in response to how I had made this meeting with Sharon. I was gutsy. It blew me away. (Conversation, May 22, 2000)

Valerie, you did not understand how Sharon could deny access to the aide to support Jason to attend the swimming pool. You were sure that the incident was over when the consultants recommended that Sharon approve the swimming program. You believed Sharon would submit to the knowledge of two other professionals at the table. Tensions continued between Sharon and yourself as you both struggled to determine who had authority. When the consultants supported your request Sharon used her authority to deny the support Jason needed to successfully attend the swimming program. This situation made evident to you that it would be necessary to carefully negotiate every step.

Whose Knowledge Counts? Placement

Valerie, when Jason was to attend Kindergarten you were cognizant that you would have to work with Sharon, the school district staff that was responsible for the school placement of students with disabilities, to secure an inclusive school placement for him.

> I knew that I was going to be dealing with Sharon after this episode (getting swimming for Jason). I was so relieved that she went on sabbatical. She was out of there. It was so stressful dealing with her because it was a brick wall. It was a personality thing. It was a control thing. A professional saying this is what has been done. You are not going to ruffle anyone's feathers. You are not ruffling mine. I am not going to let you. I was doing it and it was not comfortable. No one had questioned her expertise and professionalism before. I look back and I see that now but at the time I was mad. (Conversation, May 22, 2000)

You lost trust in Sharon's ability to hear your wishes for Jason and saw Sharon having significant influence in what the outcome of Jason's placement would be without including you in the decision. In previous interactions Sharon made clear it was she who would make final decisions for Jason. You were to relinquish decisions to her authority. Her knowledge counted, yours did not. You were relieved when you learned Sharon was on sabbatical and that you would not have to negotiate Jason's inclusion into Kindergarten with her. However, you learned from working with her that if you were to have a voice you would have to take independent action to mobilize support for your decision, to have Jason included in a regular Kindergarten, honoured.

In preparation for speaking with the central office staff, you went to your local school principal to ask if he would accept Jason. You were aware that you would need supportive professionals to secure an inclusive placement for Jason. You were confident in your ability to increase your support from others but were unsure of how the principal would respond to your request. You knew the principal through his relationship as a golf friend of your husband. You wondered if this had an impact on his decision but you were unsure. As I listened to you I wondered what would have happened if there had been a different principal? Would the answer have been the same? The decision to accept Jason seemed arbitrary, with Sharon offering the special education class while the principal, from the neighbourhood school, was saying his staff would be ready to teach Jason when he was ready. The placement 'school gate' was set high creating a hurdle you had to pass over to gain access to your neighbourhood school. After securing support from the principal you were required to return to the central office staff to gain their approval.

> I don't know if it was true but I had heard if the school was ready for your child the school board can't say no to you. I went to the school board and talked to Sam (Sharon's replacement). I told him this is what the principal said. I thought Sam was going to tell me that it is too early to make any decisions about Jason going to Kindergarten. It was January. Sam grabbed a memo and scribbled out a memo to the principal stating that Jason would be going to his school and his daycare aide would probably be coming over with him. He signed it and put it into his out

> basket right there in front of me. I was expecting the response I had gotten from Sharon. (Conversation, May 22, 2000)

Valerie, fundamentally you were concerned with your ability to have choice for your son's placement in Kindergarten. Although you were granted your request there was such a contrast between Sam's response and what you thought Sharon's would have been. How Sam exercised his professional judgment reinforced the authority of professional judgment in deciding where children attend school. The inter-professional differences that seemed to emerge, concerning Sharon and Sam's responses to your request that Jason attended his neighbourhood school, were to be erased years later. This time you were granted inclusion for Jason by Sam, but years later he retracted his support for Jason's continuation in an inclusive education setting when he was transferring from Grade 6 to 7. Sam lived the same storyline as Sharon. He is expert, he decides!

Sandi, your experience of securing inclusion for Cameron at the beginning of his school career differed from Valerie's, not only in the barriers you encountered but also in your response. You encountered your first sense of resistance to Cameron's inclusion when you met with the principal at the local school before Cameron was school age. He told you he did not think the school could accommodate Cameron. Your response to this was to educate yourself so you could respond to another professional's rejection.

> I went away and thought okay if that's the mind set then I need to get informed about exactly why Cameron should go here, what it means, what it takes and how teachers teach. I started this journey of reading everything that I could get my hands on about inclusive education, so I would never sit in a meeting and feel that

> I didn't have an answer. I learned educational language. I figured out how curriculum worked in theory. (Conversation, October 31, 2000)

You wanted to be able to respond with paradigmatic knowledge about why and how schools could accommodate Cameron. You did not want to feel silenced at a meeting again. You knew the importance of knowing educational language to be able to effectively participate in the talk about schools and children with disabilities.

> For me it means needing to understand all the expert language. I have to understand the language of education. Know how to use it. As a nurse I had to understand the language of medicine and know how to use it. It almost feels that you are dictated on this journey. Like it would have been nice to study art. (Conversation, November 6, 2000)

Having to learn how to talk to the schools, using their language, was demanding and time consuming. You shared if Cameron did not have a disability you would not need to immerse yourself in reading about curriculum and educational research. You felt having the language of the expert, being able to use it with ease, you would no longer feel like a non-expert in discussions in the out-of-classroom places on the professional knowledge landscape. Who had the knowledge could not be disputed if you discussed Cameron's inclusion from the vantage point of expert knowledge.

You worked hard to get Cameron into the preschool situated on the school grounds so others could develop relational knowledge about him. Your knowledge, both narrative and paradigmatic, enabled you to make decisions that were different from what the professionals scripted. Your decisions were not filled with uncertainty. Your work to be knowledgeable about inclusion fuelled your sense of confidence to combat the taken-for-granted expert professional knowledge script that espoused Cameron would be best served in a segregated classroom and not in the local school that shared the grounds with his preschool.

> Being part of QPPD (parent advocacy group) gave me connections with other moms and dads who were fighting for their sons and daughters to be included. It gave me an avenue to fight. They helped me understand this is the story now; this is what I do next with my argument. (Conversation, October 31, 2000)

You carried your confidence in knowing what was best for Cameron through to all levels in order to disrupt the institutional professional script that children with special needs are best educated in segregated education. A segregated special education placement was not in your imagined narrative for Cameron. You had,

> decided that everything my other kids in life had entitlement to and I wanted their lives to be, I wanted Cameron's life to be. I wanted it to be filled with friends. I wanted him to be part of his social community. I wanted him to grow up and be loved and to have relationships with other people, a good job he has a passion for. It was nothing different so that meant education didn't look any different either. (Conversation, October 31, 2000)

Your knowledge of what Cameron should have was constructed from your narrative, relational and embodied knowledge as a mother who wanted the best for her children.

Your work to understand the theoretical knowledge of inclusion helped you to see that inclusive education was a viable option for Cameron. Your notion of inclusion, for Cameron, was shaped by expert professional knowledge you gathered, such as from the presentation you saw where an international speaker put up an overhead of an image of a child being fed by a tube on the playground by other children. Your history as a registered nurse made you think, if children are capable of supporting another child to do this then the possibilities are limitless. With your newly developed expert knowledge, you maintained your passion for Cameron's inclusion in all aspects of life, including school, in spite of professional opposition. You were not trapped into the institutional narrative. You did not allow the obstacles professionals placed in your way divert you from securing inclusion for Cameron.

> The Guidance Officer would just drop in to talk to me. She thought having a series of really long conversations I would give up (inclusive education). It worked with other parents so why wouldn't it work with me? I mean if you have to have the same conversation a thousand times, people give up. I was dead sure what I wanted for Cameron. It was not what she wanted. We spent hours. I just sat and listened to her getting more pissed off with her. I knew I needed to give her the time to appear reasonable but I kept saying no. It was really frustrating. Conversations that had nothing to do with Cameron but had to do with her stereotyping kids with disabilities. It didn't reflect Cam at all. She wasn't even prepared to engage in knowing him as a person. She just wanted to do her job, which was to tell parents that they could not go to a regular school. She did it really well. It worked for most. Every once in a while she would meet one or two that didn't want to go down that path. That used to drive her insane. People spent more time and energy talking to me for two years trying to convince me.
> (Conversation, November 6, 2000)

You discovered the Guidance Officer worked from a position of 'I am the professional: I am the expert: I have the knowledge.' Your knowledge began with your personal practical knowledge. You lived with Cameron and developed narrative knowledge of him. This relational space is where you authored your knowledge of what was best for Cameron. When you entered the professional knowledge landscape, you were struck by how professionals came with a prescribed view of who your son was and what he needed. This angered you because they showed no interest in knowing your son in a relational way. They were content applying their expert knowledge. The abstract talk shaped by policies and prescriptions for children with disabilities did not fit Cameron. In the Guidance Officer's view it was the expert professional knowledge story that would be followed. You were expected to spend hours listening to the Guidance Officer's words as to why Cameron could not be included. Telling and retelling the same story as to why you would not approve a segregated setting for Cameron was equally exhausting. I could hear this in your voice as you related this story to me.

Although you worked to "fill up the tank of knowledge" and were sure of what you wanted for Cameron just as Valerie had been for Jason, you needed professional allies. Professional support came primarily from the staff associated with the early intervention program. A key player in this support was Bernie. He was the husband of the Director of the early intervention program. Jan had recently passed away. Upon Jan's death Bernie came forward saying he wished to carry on with her work by standing by parents, helping them to secure inclusive education for their children. You were pleased to have Bernie at your side. You said, "He had a real presence about him. Everyone thought he was my lawyer. I never told them any different. He would just sit there and take notes through the meetings" (Conversation, October 31, 2000). You contested the expert paradigmatic knowledge, on the out-of-classroom places on the professional knowledge landscape, with the appearance of having your own expert. At one particular meeting, close to the deliberation around the final decree as to Cameron's school placement, Bernie spoke out about the flawed nature of the ascertainment meetings. You had both sat through a very long meeting with the expert professionals, 17 of them, each telling you what Cameron's deficits were and why inclusion was not a viable option for him. In disgust Bernie said,

> I have to tell you, I am the father of four children. They are all adults now. There is not one time in my children's lives that I have ever sat through such a disgusting event. I think you all should be ashamed of yourself. (Conversation, October 31, 2000)

Leaving the meeting Bernie told you, "I am really pissed now. We are going to do whatever it takes" (Conversation, October 31, 2000). The professionals ignored who Cameron was as a person. This was at the heart of your and Bernie's anger and frustration. They storied Cameron as a set of deficits, rendering him as 'other,' not worthy of attending the neighbourhood school alongside his brothers. You knew your son better than the professionals did. You would not allow them to put him aside in a segregated classroom, a place you knew would kill Cameron's spirit. As you said,

> I don't ever want Cameron's eyes to look like the eyes of those kids. When you look into children's eyes that live in institutions they look hollow. You just go into this world of darkness. I want Cameron's eyes to have a sparkle of life in them. I want him to take risks and challenges, seeing how ugly the world can be

> sometimes. It is still better than being labelled and locked behind doors. (Conversation, November 6, 2000)

It was your early years, nursing in an institution for children with disabilities, that you reflected on when you shared why you fought to secure inclusive education for Cameron. This storied past was part of your knowledge that propelled you to want a different place for Cameron. Your knowledge of what was best for your son was going to count, no matter what the professionals did or said. You and Bernie were going to make sure it did.

Whose Knowledge Counts? The In-Classroom Place

Sandi, when Cameron started school, you played an active role in Cameron's day-to-day education. Your situation was different from Valerie's for two reasons. First, the school required you to supervise Cameron on the playground. The school staff was concerned with liability of "duty of care" in relation to Cameron's safety. Second, your knowledge was a welcomed resource to the classroom teacher. You talked about how the teacher and you worked to make school successful for Cameron. You made yourself available to the teacher to solve problems as she encountered them. The teacher eagerly welcomed your knowledge and the resources you brought. The in-classroom place on the professional knowledge landscape was a safe place you helped to construct with the teacher.

> I made sure I was available. If there was a problem we found the answers together. If there was a problem the teacher knew that I would be there to support her. I tried very hard to make it that we were a team. She could air things with me

> and up to a point I could air things with her. She wanted it to be the best, her best for Cameron. (Conversation, November 6, 2000)

The barriers you encountered during the ascertainment process of whose knowledge counts had been lifted. This was a fundamentally different place. The storied landscape was shaped by your narrative knowledge as you worked for a positive outcome for Cameron. You worked as a team, authoring Cameron's school story together. Your knowledge was welcomed.

In moving from one state to another, you needed to work with a new school and different teachers to create what you had experienced in Cameron's first year of schooling. When you moved, all the boys were required to repeat a grade. Cameron entered Grade 1 again. As part of your move, you started to work full-time on a university degree, which curtailed the time you could give to the school. In spite of this, you still made yourself available. This teacher, too, welcomed your knowledge and accepted your support in working out curriculum for Cameron.

> The teacher worked hard. She had gotten Cameron a laptop computer through her networks in the community. He had all this technology that surrounded him. We had the laptop for typing because he will never develop the muscle tone to write. He had this communication device that he knows better than anyone else. I helped by showing her how to modify curriculum using the technology. You use the DynaVOX for spelling words. You know he is not going to do that physically so I put it on there and he recognizes that it is generating spelling. (Conversation, October 31, 2000)

There was a collegial sense between the two of you throughout Cameron's first year at the school. This was to change in the second year. Although you remained active in your support to the teacher, she sought help from the Education Department. She appealed to "outside" experts off the school landscape to gain what she saw as necessary supports and resources to complement her willingness to include Cameron. You shared that the teacher "was getting increasingly stressed by the lack of support. They (Education Department) don't actually support teachers to support kids" (Conversation, October 31, 2000). The lack of support from her professional colleagues at the Education Department pushed the teacher to transfer her support away from Cameron's continued inclusion. She suggested Cameron attend a lower grade in the morning and an age appropriate classroom in the afternoon. This suggestion was made because the professional expert knowledge, which the teacher sought from the Education Department, was not forthcoming. Her investment had been considerable. Your knowledge began to be dismissed as the teacher wanted acknowledgment for her efforts from the Education Department. The teacher wanted support in the form of expert professional knowledge and allocation of resources that the Education Department had the authority to distribute. Your knowledge, which previously had been valued and incorporated in the planning for Cameron's inclusion, was no longer welcomed at the end of Grade 2.

In Cameron's third year of school you were busy with your studies. As you said, "This year has probably been the year that I probably paid less attention to school" (Conversation, October 31, 2000). However you made it known that if help was needed you would make yourself available. You were never asked for help. When you made suggestions they were ignored.

> Every year my first argument is, "Do not sit Cameron on the edge of the classroom. He needs to be in the middle of the kids." The response is, "No we cannot arrange the classroom this way. He can stay where he is. It is because of the computer cords." Both of his devices have batteries. They don't need to be plugged in. But their response is, "There is this cord they need to be plugged in so Cameron always needs to sit next to the outlet." (Conversation, October 31, 2000)

Your advice to place Cameron in the middle of his peers to accommodate his visual learning style went unheard by the Grade 3 teacher. Your knowledge on the in-classroom place was silenced. Only professional knowledge was valued. This was reinforced when I visited Cameron's classroom. As a visitor to the classroom I, too, noted that Cameron, a visual learner, was positioned away from his peers against the wall close to an outlet. The program assistant, who assisted Cameron in the classroom, positioned herself in a way that made Cameron unable to see his peers. I mentioned this concern to the teacher. The following week, visiting the classroom again, I observed Cameron was seated at the back of the room in the middle of the classroom. This location allowed him access to an outlet and a clear view of his peers. This experience reminded me of the role expert professional knowledge has in creating and maintaining professional authority. My suggestions were no different from yours, Sandi. However, mine were acted on almost immediately. My collegial connection to the teacher, as a member of the same expert professional group, carried with it power to influence the teacher. My knowledge counted, yours did not.

Whose Knowledge Counts? Relentless Pressure for Segregation

Valerie, when you were planning Jason's move from elementary school to junior high school you were to encounter Sharon again. You spent the last seven years, with Jason in elementary school, awake to knowing what was best for him. You had constructed your knowledge about Jason and his learning in partnership with the teaching assistant and his teachers. However, with the transition to junior high your wishes, once again, were going to be seen as part of a competing story. You were to be reminded that professionals on the out-of-classroom place on the professional knowledge landscape were living a story that did not value your knowing.

> There was no way Sharon was going to give Jason inclusion in Grade 7. It had nothing to do with Jason it had everything to do with her control. The Board supported her so much. They supported her at such an incredibly unquestionable level. They didn't question anything she did. (Conversation, June 19, 2000)

Valerie, you felt Sharon's longevity of experiences as a professional was seen as giving her the authority to decide Jason would be best served in a separate classroom for Grade 7. Jason's transition to Grade 7 was not to be participatory – there was to be no valuing of your knowledge in deciding where Jason would attend Grade 7. Jason's narrative, lived across time in the elementary school as a successful student, was dismissed.

You confronted Sharon's knowledge that Jason would be best served in a segregated classroom. You indicated that you would appeal Sharon's decision. Your decision to appeal set a new plotline into motion. In attempting to stop the Board from supporting Sharon's recommendation to send Jason to a segregated classroom you, with your advocate, Paul (from AACL), set a meeting with the Acting Superintendent and Sharon. You were pleased to learn that Sam was the Acting Superintendent. Based on your past experience with Sam you believed meeting with him would resolve the dispute. He would grant Jason permission to attend his neighbourhood junior high.

> When we met with Sharon and Sam I thought that it was going to be fine. I was so thrilled that this was happening before school started. Paul came with me. Sharon talked about her issues and perspective. I gave mine. Sam asked me about the hostility. That was the actual word he used; the hostility that Jason would get from school. I felt he betrayed me completely by siding with Sharon. I was mad, angry, hurt, frustrated by his decision. It was a huge discouragement for me that Sam sided with Sharon. I felt betrayed. (Conversation, June 19, 2000)

In this meeting, you felt you encountered the same storied landscape you encountered when Jason was five. Sam would determine the outcome. It was within his authority to grant permission for Jason to attend his neighbourhood junior high school. This time he supported Sharon's recommendations. Although you felt betrayed by Sam supporting Sharon's recommendation you worked to find positive outcomes in the decision. You were convinced if Sam had granted your request to have Jason included in Grade 7 Sharon would have worked to undermine it.

> I look back on it now and realize he really had Jason's best interest at heart. The hostility would not have been from the students or the teachers. Sharon would not have supported any of them. Because Sharon wouldn't support Jason the teachers and principal couldn't support him. Jason would have been a burden in the class. He would have been unwanted, just a hassle, too much energy, too much effort, a

> disruption. The school would not get support. That was not part of her program she developed. (Conversation, June 19, 2000)

While you felt betrayed you did not feel powerless when Sam upheld Sharon's decision that Jason attend a segregated program for Grade 7. You were not willing to have your request dismissed. The story of segregated education prescribed for Jason was not the one you wished Jason to live out. You saw where Jason attended school as crucial to his future life-chances. You set the appeal process in motion.

Although you were denied your request for Jason to attend the neighbourhood junior high school on the first day of school, you headed off to the neighbourhood school with Jason and friends in tow to register him. You requested the principal allow Jason to attend his school. You were called upon to defend your desire for inclusive education for your son to an unsympathetic principal. You felt forced to create public pressure to gain acceptance of your desire to have Jason continue in an inclusive education situation.

> The first thing the principal said when he closed the door behind us was, "What are you doing to me?" Before I could even react Kevin (Jason's dad) said, "What are we doing to you? What are you doing to our son? It is our son that this is all about, not you or me." The principal said, "You know this isn't my issue. You have to deal with head office." I said to him, "If you took a stand this could happen in your school. It wouldn't just benefit Jason it would benefit your whole school if you took a stand. You could do that." "No," he said, "No you have to deal with head office." Then I said, "You are telling me," he was trying to justify his response, "You are saying that Jason cannot be in your school unless he is in a separate class?" He didn't say yes or no he just tried to explain. I said, "You are

> telling me that Jason can not be in your school unless he is in a separate class yes or no?" He said, "No, you have to go to head office. He cannot be included until I get justification and permission from head office." (Conversation, July 17, 2000)

Your knowledge of the principal, who supported Jason to attend Kindergarten at his school, enabled you to protest the junior high school principal's refusal to accept Jason. You believed this principal could have put an end to your appeal if he just said Jason could come to his school. Had that happened the dispute would have been resolved. You believed he did have the power to do this. However, the principal said only if he was directed by central office could he accept Jason. The decision, where Jason would attend school, was based on policies and prescriptions the principal felt he must adhere to. With the principal refusing to accept Jason, without approval from central office, you were forced to continue with your appeal. Your thoughts were clouded with the unfairness of Sharon's refusal to maintain Jason's inclusion in Grade 7 and the impending appeal.

> The pain of them not hearing me was hard. It was a program that they had developed and Jason's being included did not fit into this program because of the money it would cost, the fact that it hadn't been done in junior high before I guess and the fear of the unknown. They didn't stop to look at him, where he was and his relationships with people. It was the placement that we were fighting. That is an educational issue. It was the way the School Board went about deciding. It is a rights issue. They put him in a slot without knowing anything about him or the place that they were sending him. (Conversation, July 17, 2000)

Valerie, the pain in your voice was poignant as you shared how the decision to segregate Jason from his friends in Grade 7 was made. The decision was made without knowing who your son was and without knowing his successes when educated with his peers. You could not understand how professionals could negate who your son was and what his relationships were with his friends at school. Your parent personal practical knowledge, constructed as you observed your son grow and succeed in the regular classroom over seven years, was not considered in deciding where Jason would attend school. You wanted the professionals to pay attention to the stories you told about your son and to understand your belief in Jason's ability and right to stay with his friends in Grade 7.

Sandi and Valerie, this letter re-presented your personal practical knowledge of your sons and how your knowledge was heard on the professional knowledge landscape. In the next letter, I shall explore your stories of school transitions.

With Warm Regard,

Heather

CHAPTER VI

TRANSITION: THREADS OF TENSION

Dear Sandi and Valerie,

A child's school life is made up of a chain of transitions taking him from one setting to another. Your stories of your sons' transitions were different than the routine transitions most children encounter in their storied school lives. By and large the transition story is home to school, primary to middle school, middle to secondary school and school to work (Blatchford, Battle & Mays, 1982). Much research has been done with a view towards making these storied transitions as smooth and productive as possible (Lord & Eccles, 1994; Marshall, 1988; Ruddick, 1996; Sieh & Gentry, 1990; Vowels & Rosa, 1989). Your unfolding stories of your experiences with your sons' school transitions did not fit the smooth productive narrative but had a sense of ongoing tension. The term 'transition' in relation to your stories of your experiences with your sons included more than the commonplace transitions children face in their school careers. Yours had many barriers to overcome.

Transition: Home to Daycare

Valerie, the added transitions Jason and you experienced created additional stresses for you as a parent. You felt times of transition demanded of you, as a parent, to be on guard and wide-awake to potential danger. Your sense of trepidation, in relation to transition, began early in Jason's life when you needed to consider where he would spend his days as a young child of three.

> When he went into daycare he was three. He was tiny, vulnerable. I don't want to do this. I knew he needed to be with other kids. Play school was an option but he

> needed a more concentrated program. He needed five days a week not just the two days with the play school. He needed more than that. He needed every day with kids. I remember being very nervous for him. I had never planned on any other person or group instruction. (Conversation, May 22, 2000)

When Jason left the world of your home and play school and entered daycare full-time it meant entering a New World, one where you had to share the care of Jason. The transition from home to school is often the first time parents are obliged to place the care of their children at least partially into the hands of another person (Blatchford et al., 1982). Your quivering voice and near tears as you talked about this highlighted your trepidation as you sent your little boy of three into the care of others. Placing Jason in the care of others before school age was not something you ever envisioned for your child. "For him to be included I have to rely on other people to make it happen. Everywhere else I could do it myself. Make it work in my own way. At daycare I couldn't do that. I had to turn him over to other people to make it happen. It was a huge thing" (Conversation, May 22, 2000). You were troubled by the notion of giving the care of your child to the daycare staff. Compounding this, giving him up to others' care, you had to trust the staff would work to include him.

You made it known to the staff that you would not surrender your child into their care. This responsibility would be shared with you being the prime mover taking action on your son's behalf.

> Even if they were in charge of him for these times it is still my responsibility. You know the responsibility is not just on your shoulders. I am not going to let you take complete responsibility of this. (Conversation, May 22, 2000)

The concern you gave voice to, having to adapt to the transition from home to formal instruction in a school setting, is not so different from those articulated by parents whose children are not disabled (Alberta Teachers' Association, 1996). However, being the parent of a child with a disability you encountered this experience earlier in your child's life, before you thought you would need to.

In addition to giving your child into others' care you were forced to deal with the expert professional discourse of knowing what was best for your child and trusting that their best interest for Jason was to include him. As you said, "Inclusion was just one of the steps of a mother loving her son, expecting everyone else to love him the same way they would love any other kid or respect him as any other kid. I just assumed that they would and should and they better" (Conversation, May 22, 2000). You wanted, and expected, the professionals to story your son as they storied other children upon the school landscape, a child who was worthy of their love and attention. You wanted Jason's story in progress to be positioned within the 'common lived experience' of his peers without a disability. Through your relational knowledge, as Jason's mother, you knew that self is formed and given meaning in the context of relationships with others. To this end you wanted the professionals to contribute to making Jason's narrative one filled with stories of relationships, which you knew would be best achieved by including him.

Transition: To School

Valerie, the picture you portrayed in your pursuit to secure an inclusive education for Jason illustrated a major transition when he entered Kindergarten. Transition to Kindergarten is a transition that schools work hard to help children through because it is known that "adapting to school is a major experience for children and parents, and there should be on all sides an awareness of the necessity of growing slowly into new stages" (Hurst, 1987, p. 95). Starting school is seen as a new and exciting stage of life and schools work to develop welcoming procedures to make an effort to make this transition to school as smooth as possible for children and their parents (Marshall, 1988).

Your retelling of Jason's transition to Kindergarten does not speak of welcoming nor was it a smooth ride. This milestone in life usually begins with a trip to the neighbourhood school to register one's child. For you it meant negotiating Jason's school placement with central office. You had had unsatisfactory encounters with the staff in charge of placement for children with disabilities and worried there was going to be a roadblock to securing a placement for Jason at the neighbourhood school.

> I talked to Sharon. She gave me the whole gamut. It's a pyramid thing. She planned to send him over to Northwood School, which is across town in the special education program. That was the pressure she was putting on me when he was five. (Conversation, May 22, 2000)

In addition to the anxiety all parents experience as their children move into formal schooling, you were placed under the strain of being pressured to send Jason away to a special education class, which required you to then have to negotiate for an inclusive placement for him. This included numerous negotiation meetings which included meetings with the school principal and central office staff.

> It was so stressful dealing with Sharon because it was a brick wall. It was a personality thing. It was a controlling thing. You know this is what has been done and you are not going to ruffle anyone's feathers. You are not ruffling mine. I am not going to let you. I was doing it and it was not comfortable there. No one had

questioned her expertise and professionalism before I guess. (Conversation, May 22, 2000)

Sharon's (central office staff) refusal to support Jason going to his neighbourhood school created tension for you as you opposed Jason being placed in a special education class. You were required to engage in further negotiation to get Jason into the school of your choice. You took it upon yourself to meet with the school principal to seek his support for Jason's placement in the neighbourhood Kindergarten class. The elementary school principal expressed his readiness to have Jason in his school. However, you still returned to central office for approval because you were unsure, even if a principal was supportive, could central office refuse to support the request. You were not sure what Sharon's response would be and were apprehensive because you were not certain if having the support of the principal would be sufficient to change Sharon's mind. You were to learn that Sharon was on sabbatical and a new staff member was in her place. Upon sharing your story and the support you received from the neighbourhood principal to accept Jason, the new person approved your placement request and Jason started Kindergarten the next fall in his neighbourhood school.

Sandi, Cameron's transition from pre-school to public schooling had you consumed in the ascertainment process. The process was time consuming and emotionally demanding. You knew what you wanted for Cameron, which was to attend his neighbourhood school with his brothers, "growing up loved and having relationships with other people. It was nothing different from his brothers so that meant education did not look any different for Cameron" (Conversation, October 31, 2000). To get what you wanted for Cameron you were required to participate in a series of monthly meetings comprised of professionals "telling the deficits in your child" (Conversation, October 31, 2000). You shared how these meetings were confrontational and that most parents gave in after two or three meetings allowing the professionals to determine what was best for their children and you said it was only "stubborn nuts like me that go on to fight it" (Conversation, October 31, 2000).

You shared your determination to secure inclusion for Cameron was driven by his will to live. Because of his resolve, you were not willing to allow Cameron to receive the morsels that the Department of Education were prepared to give him. The crumbs of special education were not going to suffice. As long as he could get up in the morning you would stand beside him. Standing by Cameron meant combating professional gatekeepers that dispensed the Department of Education's crumbs.

> November before Cameron was to start school there was this coordinator meeting that I went to. I arrive at this meeting and there were seventeen in the room and Bernie (a friend) and I sitting there. Every person went on to tell me Cameron's deficits and why it was absolutely impossible, why Cameron couldn't go to school. There was one of the speech therapists from the early intervention there, thank God, because she kept saying Cameron had really good signs of early literacy. There were three of us fighting for Cameron and everyone else was saying it is impossible. (Conversation, October 31, 2000)

Sandi, you battled against the predetermined limits the professionals offered Cameron. This battle continued when you received the professionals' reports after the meeting. You shared the reports were written from a deficit model and never identified Cameron as a human being. In response to these reports you set about to demonstrate how they did not reflect the boy you lived with. You prepared a counter response to the reports, which you forwarded to the individual in the Department of Education that would make the final decision. You were distressed by the fact that one person would make a decision about where Cameron would go to school when they only had expert paradigmatic professional knowledge to rely on.

Biklen (1988) argues that professionals typically provide service to people with disabilities from a clinical perspective. Due to an individual's disability-related needs, one becomes captive of a treatment model. This model places people with disabilities in a client role thus making many aspects of their lives subject to professional authority. In education, professionals exercise their expert professional judgment in determining appropriate educational programs for children with disabilities. School related professionals operate from a model of individual assessment, diagnosis and placement. However, the professionals' placement decisions are further affected by the limited choices available to them within their environments. Biklen asks,

> do professionals truly have the freedom to exercise professional judgment, or are professionals and consumers alike merely functionaries and pawns in a world of narrowly restricted parameters in educational placement? … In other words, does the context for professional decision-making allow for the independent exercise of clinical judgment or, instead, are professionals severely constrained to make decisions within limits that may not be supported by research, stated policy, or clinical judgment. (pp. 129, 133)

Biklen questions if clinical judgment operates in an ideal form because aspects such as social, economic and political factors drastically limit professional judgment.

There is a perception that student placement decisions are made purely within the expert professional domain when in fact they are based on a range of factors that limit the professionals' judgment. As Biklen states it is necessary to understand this to dispel the myth placement is based on clinical judgment and to see placement recommendations are made based on institution limitations placed on the professional. Understanding this would allow for the recognition placement decisions concerning children with disabilities is a rights issue rather than related to the child's disability.

Sandi, you decided you would dispel the clinical myth of professional judgment. Along with your written critique of the expert reports, in which you pointed out all the inconsistencies and things that did not make sense, you made a video of Cameron with the family and sent it to the woman in the Department of Education. You wrote to her and said, "If you are going to sit and pass judgment on my son then you should have some context as to who he is" (Conversation, October 31, 2000).

The decision was to come in a conference call, which you were to be in attendance for, as part of the ascertainment process. The call did not play out as it should have and you and the Department of Education representative were the only ones online. You asked if she received your video and she responded with

> … laughter on the other end of the phone and said, "Yes I did get it. It was quite a powerful statement." She went on to give Cameron a Level 5 which meant that he would go to the local school. We had just got our foot in the door after two years of meetings. It felt like thousands of hours of meetings. (Conversation, October 31, 2000)

Your struggle did not end when the Department of Education gave approval for Cameron to go to his neighbourhood school. You encountered other barriers of resistance from both the principal and a parent.

> I was on a committee (for the school) to support a friend to write a submission for computers. One night the meeting was at my house. All of us involved came. This one woman sat at the end of the table. She was a teacher. She said, "I want to know if you are going to continue with this ridiculous notion of including your son at our school? It makes absolutely no sense and if you are I am resigning from this committee." (Conversation, October 31, 2000)

Her comments caught you by surprise. I could almost feel the tension that must have been in the room when this happened. You described the knot you had in your stomach when you told her that Cameron would be attending this school. She got up and walked out. I was uncomfortable when you shared that this parent was a teacher by profession. As I listened to you, my mind flooded with comments that my friends, who have children with disabilities, endure when others see their desire for inclusion to be inappropriate. How I cringe when they begin by saying, "Do you know what my child's teacher said to me today?" I too have heard these sorts of comments as a teacher when advocating with a school staff for adequate supports for a child with a disability. One time a colleague said her students deserved more access to assistance from the school aide than Susan did (Raymond, 1995) because her students were not mentally retarded and they would actually benefit from the extra instruction time. She said Susan, being disabled, would not benefit. While this and other stories of rejection were hurtful to me, they must be so much more searing when aimed at your own child. Thank goodness your story had a positive turn.

> My friend said, “I am glad you did that. I couldn't stand her.” Then we had this amazing conversation about why we chose inclusive education. At the end of the meeting everybody walked out with a real sense of 'we will all support you to do this.' It could have gone to a disaster but it was really positive. (Conversation, October 31, 2000)

However, this parent's desire to deny Cameron's access to his neighbourhood school did not stop at this meeting. She continued her lobbying and took it to the school playground where she met one-on-one with parents to rally them around her cause. Your strength came through as you shared that you had gone to the principal and told him, "Tell her to stop or I will take her to the anti-discrimination board. Tell her to be quiet yesterday. I don't want to hear it any more" (Conversation, October 31, 2000).

Upon quieting this parent, you then had to do battle with the principal twice. First he refused to allow Cameron to attend the pre-school full-time due to inadequate resources. You responded by securing volunteers to assist the school and would not allow the principal to prevent you from creating and supplying the school with this team of resource people. The second battle placed you and Cameron in the public eye when the principal organized a meeting for parents to discuss Cameron being a student the following year. You were angry when you discovered the principal organized the meeting. "It was on a flyer and put into every one else's pigeonhole except mine" (Conversation, October 31, 2000). You decided to attend and felt like Daniel going into the lion's den. Your calmness about this situation was inspiring for I do not believe I would have promised myself, as you did, to be calm and patient as you listened to what others had to say.

> I went alone but I knew friends were there. I knew that I would have a supportive voice. Nearly every family was there. Some fathers and as well as mothers which was really unusual. The principal did a better job of managing it than I thought that he would. I can't remember the specifics of the conversations. But I had spent a whole heap of time listening to people's concerns, which he addressed really well. In response to Cameron taking extra time he talked about Cameron's aide being there to support all the children in the classroom and not just Cameron. There would be another pair of hands. I was actually very surprised. He did a good job. (Conversation, October 31, 2000)

The tide was turning for you. The principal showed leadership in shaping positive attitudes towards Cameron as a valued member of the school. He was not the only professional that stood by your request. The teacher proved to be supportive and expressed, with enthusiasm, her desire to have Cameron as one of her students.

> The teacher was there too. She was really interested in having kids with disabilities in her class. She talked about her experiences of including a couple of other children and felt really positive and excited about these experiences. (Conversation, October 31, 2000)

During the meeting you spoke up to offer your support to help the class and parent community to learn about Cameron and his needs. You indicated you were open to addressing any concerns they may have and that you would work with them to seek resolutions.

> I spoke lots at the meeting. I said, "I was happy to engage in conversation with other parents at any time if they were having problems or there were issues needing to be addressed. I was open to listening to them and trying to get to a resolution." They (the parents) were comfortable and they knew that Cameron would be there next term and that we would have a teacher aide, that I would be around to support Cameron and that we would work as a community to make it happen. (Conversation, October 31, 2000)

The outcome of what looked to be a very stressful and combative meeting ended in a positive experience for all. For me the success of the meeting was the collaborative dialogue that emerged. I am left wondering what the principal's intention was when you were not invited to attend? Had he feared that the community would be hostile? Had he thought you would be unreasonable? How had your strength to attend and remain calm influenced the conversation? Had the community responded positively because those in authority were supportive or because you were so level headed or both?

Transition: Program Assistant

Valerie, your story of transition includes more than place. It includes tensions with changes in teaching assistants. You worked hard to establish collaborative relationships with Jason's assistants, as they were central in the communication between home and school. You had a good working relationship with Jason's daycare aide. You wanted this aide to follow Jason into the school system to make his transition as smooth as possible.

> I told him that I want his aide from the daycare to come with him. (Conversation, May 22, 2000)

Your request was granted. You had one less worry when Jason started school. When a new aide needed to be hired for Grade 1, you were once again anxious. Although you trusted the school you were concerned that the principal would not make the right choice of assistant to work with Jason.

> They were doing the right things for Jason and when it came time for hiring I just trusted him. I did ask him about being a part of the hiring. I did address this with him and he said, "You need to trust me." I said, "I will but don't you betray it. I do trust you but make sure you do this right." (Conversation, May 22, 2000)

You prayed that the right aide, the perfect person to grow with Jason, would come into his life.

> I really prayed about it and left it with the Lord. The principal asked me what I wanted to see in this aide. He was thinking about this Susan. I said, "Susan is not going to cut it. You need to hire someone that is tough as nails. She is not tough enough. You not only need to hire someone that is tough as nails but also someone who will love him unconditionally." (Conversation, May 22, 2000)

Valerie, you remained guarded in your trust concerning the new aide for Grade 1. However, as time progressed you became aware of how this aide was the right person for Jason and you began to place your trust in the aide.

> He listened to me and hired this other woman. She is the mother of three girls and has huge expectations of her kids. In fact I had a hard time with her at first until I realized it was because we are so much alike. The Lord gave Jason someone like his mother who wasn't his mother in school. (Conversation, May 22, 2000)

You were to develop an unwavering trust in this aide as you learned that you both had much in common.

> I completely trusted her. The school would not allow her to transport him to the swimming pool. So I would pick them up at the school and we would go over to the swimming pool. Through this I realized that by some of the things she was saying that she was a Christian. So the Lord gave him someone that was really like his mom. That was important to me. He had someone that knew the spiritual side of him, the God side of him. That was critical and when I'd say we need to pray about this she would know. She wouldn't look at me like I was weird. Like I was totally out to lunch like a fanatic or what ever. She knew and understood immediately. (Conversation, May 22, 2000)

Sally stayed as Jason's aide from Grades 1 through the end of Grade 5. You had come to rely on Sally to be an advocate for Jason at school. This allowed you to gain greater trust in the school's effort to provide Jason an inclusive education.

> Sally was incredible. I never worried in elementary school. I completely trusted her. I had some trouble with teachers but because Sally was there I never had to advocate for him in elementary school, very seldom, because she did it. She had the energy. She had the drive. She saw the potential in this child. (Conversation, May 22, 2000)

Before the end of the fifth year, you learned that Sally was moving communities. The school needed to hire a replacement. This was difficult for you. However, you continued to trust the school and assured the principal that if Sally was part of the interview panel for the new aide you had faith in their ability to find the right teaching assistant to replace Sally.

> I told them as long as Sally was involved with the interview I didn't need to be there. It was a new principal and he was okay I thought. I said, "There is no need for me to be there if Sally is involved in the interview because we are on the same wavelength." Furthermore she was more involved and knew Jason's needs in school better than I did. I trusted her completely to be involved with it. He ended up interviewing this person and offering her the job on a day that Sally was away. I felt so betrayed and so worried for Jason. (Conversation, June 5, 2000)

Your trust with the school disappeared. You remained concerned throughout the summer and fall. You did not want to be critical of the new aide but you could not shake this feeling of unease as you tried to work with her.

> The warning bells were clanging. I thought okay I couldn't be too critical here. By the end of September I was holding myself back because I needed to be fair to her. Everybody is going to think that I wasn't if I pulled the plug. I knew that immediately they would think that I wasn't being fair to her, that I was comparing her to Sally. But it had nothing to do with that. It was these entire little common sense adult-child things. They were common sense ways of being with kids. (Conversation, June 5, 2000)

Your tension around Jason's transition into Grade 6 and his working with a new teaching assistant never subsided. The year became worse. Jason began to show signs of stress through having toileting problems and behavioural outbursts. Your interactions with the school staff became increasingly troubling to you and left you with many concerns.

> I started seeing a pattern of how she had been setting him up for failure. Telling him that he couldn't do stuff that he had always done. She was doing things that were making him a burden to the classroom. She was doing things that were making him a load to carry, an unwanted load not an extra challenge or a responsibility but a burden. This was starting to interfere with his relationships with his friends. As the year progressed I heard things in the community from parents in other classrooms. This was just kids' moms in Grades 2 and 3 and 4 and when they saw the aide interact with Jason they could see a good thing wasn't happening. It left the year in a big mess. I could tell right off the bat that she wasn't doing the right thing. (Conversation, June 5, 2000)

For you, Valerie, the transition to a new aide was very difficult. You found when you tried to discuss your concerns with the assistant, a wall went up making the year very difficult for both you and Jason.

Transition: Junior High Inclusion in Question

Valerie, when Grade 7 was on the horizon, with the junior high school and students preparing for the transition, Jason's transition to the 'big school' would not be made with ease. For Jason's peers, it meant moving forward, leaving behind another part of childhood as they reached another milestone in their school life.

> Junior high beckons "like the land of milk and honey," says Richard Sloves … It's their entry into adolescence. The benchmark for what it means to be older." (Hartman, 1996, p. 12)

For Jason this transition was not to be a 'land of milk and honey.' You were to learn that Jason's transition to junior high was not to be with his friends. Rather he was to be sent away from all that he had known throughout his elementary school years, leaving his friends behind, moving to a segregated class. Jason's continuity in an inclusive education was in jeopardy.

> I had talked to the junior high principal about Jason going into some of the Grade 7 classes so he would get to know the teachers. And some his teachers going into some of the Grade 6 classes so they could get to know Jason. He said, " I need an okay from head office." He calls Sharon in a panic because this is what I was expecting. And he was not going to let it happen as far as he was concerned. (Conversation, June 19, 2000)

As the other students planned their transition to junior high with their parents and school staff, it was necessary for you to once again negotiate Jason's inclusion with Sharon, the central office staff that resisted Jason's inclusion in Kindergarten.

> Sharon phones me this one morning and says, "I need you to come in at 11:30 today and you are not going to like some of the things I have to say." What I should have said was, "No I can't come. We will need to schedule it for another time." I didn't realize this so I said, "Fine" and I phoned a half a dozen of my friends and said, "Start praying, I don't know what is going on." (Conversation, June 19, 2000)

Valerie, for you this meeting was encountered with dread. You were forewarned that you were to hear bad news. You responded by creating a circle of support by calling friends, asking them to pray for a positive outcome. At the meeting you were to learn that

Sharon would not support Jason's inclusion in Grade 7. She would be recommending that he be sent to the segregated program at another school because their district had never done inclusion at junior high and it would cost too much to continue to provide Jason an inclusive education. Sharon also expressed the view that Jason's friends would be too stressed to have a friend like him in Grade 7.

> I told her, "You don't have any idea about what my son's relations are with his friends. You don't have a clue. His friends when they are really stressed they seek him out because they know he will listen to them. He listens to them. He is someone they can trust. He is not going to criticize what they say and they may not get the hugs they want but he is there for them. That's the kind of relationships he has. Don't you tell me what you think will happen. I don't expect him to have tons of friends in junior high. If he has one or two that is all his brother had. That's all that matters." I said she insulted him again and I told her I didn't trust her. (Conversation, June 19, 2000)

The hurt in your voice and tears in your eyes when you shared what Sharon said was heart wrenching. You wondered how you were to tell your son that those in charge had made the decision to prevent his continuation in school alongside his peers.

> How could I tell a thirteen year old boy, going into adolescence, that he worked so hard all these years to be in the world and be successful there and be welcomed there that it didn't matter because he was still too different. I just told her I wouldn't let you say that to him. (Conversation, June 19, 2000)

Like other parents you wanted to protect your son from hurtful experiences and this was one of those situations that you felt you needed to safeguard Jason from. As you told this story I thought about Linda's experience when she had to tell her son he could not go to school with the friends made over the summer, that he would have to return to the segregated school rather than attend the neighbourhood school where he could walk with his friends. Did Linda agonize like you did when she came home each evening after one of the nineteen school visits she made? I wonder what she told Paul after each of the rejections she received.

Although it was clear you wanted Jason to continue in an inclusive school arrangement, Sharon remained adamant in her recommendation that Jason move to a segregated classroom for his junior high years. Your refusal to allow Jason to be trapped in the traditional plotline of segregated education for children with disabilities resulted in a legal placement appeal.

Transition: Moving to a New City

Sandi, in the middle of Cameron's first school year, your marriage ended. This circumstance forced you to move back to your home state to be closer to family for support because you were now a single mother with three boys. In preparation for the move you sought advice to determine where you would look for a house in the city to be near a school that would accept Cameron.

> Before I left Queensland I did a whole heap of research about where do you go in Adelaide. I'd met Lorraine Zeni (an advocate from Adelaide) at the Wolfensberger's course and said, "Tell me what do you know about schools in Adelaide." With the possibility of going I had a clear picture in my mind where we would settle. I got a house in the area that I knew would have Cameron. (Conversation, May 22, 2000)

Sandi, just as you decided to move to a neighbourhood where the school would accept Cameron, I have heard other parents say their decision of where to live depended on a school accepting their child with a disability. One example was when colleagues, who returned to Edmonton from living in Toronto, bought a home in their old neighbourhood. Not because they wanted to live there but because they knew the school would be willing to provide an inclusive education for their son with a disability. School choice, by parents of children without disabilities, is an area that significant educational research has been conducted (Coldron & Boulton, 1991; Goldring, 1991; Hunter, 1991; Stillman, 1986). The purpose of much of this research has been to understand how to market schools to students. West, David, Hailes & Ribbens, (1995) and Smedley (1995) in their research on the process of how parents chose schools stated the most frequent reason parents select a school is based on the school's close proximity to home and whether siblings had attended the school. The neighbourhood school was the natural destination for a child. While this is the main reason parents of children without disabilities chose a school, parents of children with disabilities do not have the same option. Sandi, you needed to be proactive in seeking a school for Cameron based on their willingness to accept him. You could not choose any local school that you resided close to like other parents could.

Sandi, I wonder how you might have chosen where to live if you did not have to worry about Cameron being accepted. If every school had the same degree of respect for your child and all schools provided an inclusive school placement, where would you have lived? Closer to family? Closer to friends? Closer to your eldest son's high school? What you did seemed necessary. It was a way to decrease the energy needed if you landed in a neighbourhood with a school principal who would not willingly accept Cameron.

> So we went to our local school in the community. I walked up and just said, these are my three children and they are coming here. I talked to the school about Cameron. They said, "What do we need to organize?" We talked about what they needed and Cam started a week later. (Conversation, October 31, 2000)

York-Barr, Doyle and Kronberg (1995) say transition for students is about movement between educational settings with a feeling of safety, belonging and support. Transition is about creating continuity of programming and the need to establish or maintain social connections with peers during and after the transition with a focus of establishing some degree of familiarity with the new environment. In the transition process for adults, within schools, educators seek to create a sense of belonging and participation among the students and adults. They work to establish collaborative relationships between sending and receiving teachers and share information and expertise about teaching the students and the context that will support and facilitate student-centred goals. Cameron's transition to the educational setting in your home state was one that had a feeling of safety, belonging and support. The school focused on establishing a degree of familiarity with Cameron and what they needed to do to make this transition smooth. There was a collaborative relationship between you and the school staff with a focus on Cameron.

Transition: Grade to Grade

Valerie, the elementary school years from Kindergarten to Grade 5 also had a sense of safety, belonging and support. Teachers worked to help establish and maintain social connections between Jason and his peers during, and after, transitions. Teachers worked to establish some degree of familiarity with Jason before he moved on to their class. Your battle for Jason's acceptance was diminished and there were many small wins of acceptance along the way as Jason moved from one grade to the next. You voiced the comfort you gained from a supportive school environment. This was a period of relief and allowed you to build a trust with the school.

Jason - Kindergarten

> I remember the first time Jason's aide was sick. The school called to say she would not be at school and could I come right now to meet with the principal to discuss how to handle this. I had addressed this concern at the daycare. Because his aide's children were sick and she had to be home with her kids rather than work with Jason he paid the price. He had to stay home. That was the way they did it. I didn't think it was fair. I thought that this was what was going to happen in school too. This was school, it wasn't daycare stuff, playtime. This was serious stuff. He needed to be in school. I went to school ready to defend this. The tears were starting to come. The emotions were sort of flowing. The principal said to me, "We just want to confirm with you that what we are doing is okay with you. We phoned a sub to come in for the day. What do you think? Is that okay?" Then the tears really came. I told him I expected you to tell me that he was going to have to come home. They were supportive in every way. (Conversation, May 22, 2000)

Grade One

> Jason's Grade 1 report card wasn't a regular report card. She sort of typed it all out. It was exciting to read. She was excited over the little things like Jason finally coming to the front to do sharing time. The first time he actually spoke to her and how excited she was about that. (Conversation, June 5, 2000)

Grade Two

> She was a great teacher. It was such a sense of relaxing and not worrying about Jason in her class. I went to the teacher interviews and she was the first teacher that really saw or told me about seeing the influence that Jason had on the rest of the class. (Conversation, June 5, 2000)

Grade Three

> In Grade 3, his teacher at the end of the year gave me a gift. It was a geranium, a potted geranium. She thanked me for the privilege of teaching my son. That was incredible. It was like, "Wow. Are you kidding? This is for me?" It was pretty neat. She was the only one that ever did this. (Conversation, June 5, 2000)

Grade Four

> In Grade 3, Jason's Grade 4 teacher came to his class to make some kind of connection with him before the end of the Grade 3 year. (Conversation, June 5, 2000)

Grade Five

> Then when he went into Grade 5 this was probably his best teacher. He was very supportive of Jason. He used to tell me stories about having Jason in his class. (Conversation, June 5, 2000)

Valerie, you worked with the school staff throughout these years to help Jason gain confidence in his ability to cope with the many transitions he faced. Throughout the years you participated actively in Jason's education and particularly with each year's transition to gain reassurance that the school staff were working to make the transitions as smooth as possible.

Grade Six

This sense of security was to disappear when Jason got ready to move to Grade 6. Jason's Grade 6 teacher was excited about him joining his class the next fall until he learned that Sally, his aide since Grade 1, was transferring to another community. His pleasure and desire to connect with Jason disappeared.

> The Grade 6 teacher had been quite excited about connecting with Jason that whole year knowing that this class was moving up to his class. He had been sort of popping in and out of the classroom at the end of the day or breaks. He would pop in and talk to Jason or say hi to him, even if Jason ignored him, just to connect. He was quite excited about it until Sally said she was going. Then fear overwhelmed him. He panicked knowing that he was not going to have her to get him through his year with Jason. He shut the doors on Jason after Christmas. It was due to his fear. It was sad to see it. It was not only sad for Jason but also sad for the teacher. (Conversation, June 5, 2000)

With Sally leaving and the hiring of a new aide, you were faced with a crisis in your trust in the school and their support for Jason. You were disquieted and worried for Jason. You remained wary throughout the summer and into the fall as the new aide took her place as Jason's assistant. You remained apprehensive about the aide's ability to guide

Jason's education program and became increasingly concerned as the year progressed. The year did not improve. At the end of the year you learned that Jason was to be denied continued inclusion for junior high.

Grade Seven

The transition to Grade 7 was not to happen for Jason. He was not to move up with his friends. Valerie, this was an agonizing year for you. You would once again be forced to advocate for Jason's right to be included. It became a legal battle with the district.

> After that meeting I sent the letter to the junior high school principal. He sent a letter back to me or phoned me and said he couldn't, you know, it wasn't his jurisdiction to look after this. It had to go through head office. He had phoned Sharon and sent her a copy of his letter. Then I sent her the same letter. That was before our conversation. She phoned and answered some of my questions. She said that she would also get a letter to me in the mail confirming her statements. I said, "We would be appealing her decision." I asked her, "Is there absolutely no way that Jason will be completely included in Grade 7? Is that what you are saying to me?" She kind of hesitated for some reason and then said, "No, he won't be." That is when I said, "Then we will be appealing your decision." I said, "In your letter list all our options." She did. Right after that Paul from AACL (Alberta Association for Community Living) recommended that we get a lawyer. (Conversation, July 17, 2000)

Jason spent the year at home while the legal proceedings slowly moved on. When the Grade 7 school year came to an end and Jason's peers looked forward to moving on to

Grade 8, you were left hanging, not knowing if Jason would make this transition with his peers. It was not until the end of the summer that you and Jason were to learn the School Board was going to allow Jason to return to school in regular Grade 8 classes. A change in players occurred just before the decision was made. The superintendent returned from a sabbatical and Sharon retired.

Grade Eight

Valerie, you successfully fought the school board decision to deny Jason an inclusive education and Jason returned to school for Grade 8. Although this was a victory you were anxious about what Jason's return to school would bring.

> They hadn't a clue, the deep fear that I went through. When that was decided, to go into Grade 8, I came home and I was in shock. It was over. He could go to school but I was terrified for him. I was terrified of the hostility. I was not completely convinced that it wasn't going to be there. That it was over. I was sitting out back and the cold was coming inside me. I was so afraid for him. They didn't have a clue. They just thought I was pushing him on them. They had no idea. It is just being a mother and having fears like every other mother does for her sons or daughters in general. They have no idea. When he went back to school I prayed for him. I was afraid for him. (Conversation, June 19, 2000)

Jason had a smooth transition back to school and, through this, your trust in the school was restored.

> In junior high the teachers' attitudes were totally different than the ones in elementary school. They told us that it would be hostile. The teachers didn't want him there. It was the opposite of that. As much as the teachers were fearful, they

> tried. And even in high school, one teacher I saw today, he is so excited about Jason being in his classroom. He wanted to know what he could do to make the classroom more comfortable for him to develop a relationship with him. (Conversation, August 28, 2000)

This trust continued into his high school year and, Valerie, you foresee this trust continuing as Jason moves through the grades at the high school.

Cameron - Grade One

For you Sandi, Cameron's Grade 1 experience was positive. The teacher in Brisbane, with whom you worked relentlessly to develop and construct meaningful curriculum for Cameron, was open to your suggestions and worked with you to ensure Cameron had a positive school experience. When you moved to Adelaide Cameron again encountered a teacher, in his first year, that was eager to advocate for his needs. You started university when you moved to Adelaide and informed the school you would not be available to guide them at every turn as you had in Brisbane. Even with less involvement you saw many positive things happen that year for Cameron. "The teacher that had Cameron was a really wonderful human being and she worked really hard to do everything that she could to include Cameron" (Conversation, October 31, 2000). The teacher's willingness to do her best for Cameron made this transition as smooth and productive as possible. The teacher's interest in Cameron continued to be present as illustrated by times such as when you asked her to try new things like a communication device for Cameron.

> Cameron doesn't talk. This is a real big problem because teachers rely on oral feedback. I presented her with this communication device that was like walking

> onto a space ship. She just did everything she could to make it happen. We sat together and worked out curriculum. The first year at school was really positive. (Conversation, October 31, 2000)

You were relieved about this level of support for Cameron because you were working on your degree and building relationships with your family again. You needed to make connections with old friends and help the boys to make new friends. Relocating was a lot of work and this was a very busy year for all of you. However, as you told me, you survived the year and the level of school support helped lessen the load.

Grade Two

The following year Cameron's first year teacher asked to have Cameron again. The teacher felt she knew him and it would make for a smooth transition. You were apprehensive about this but agreed to have Cameron remain in her combined Grade 1/2 class. Your apprehension was soon to be lived out as the second year progressed. Concerns arose when his teacher began to feel she was not receiving support from the Department of Education.

> The teacher was really good. She kept asking the Department of Education for resources and help. What really makes me cross in South Australia is they have this fabulous policy about inclusion but they actually have no expertise in people to support teachers to make it happen. The teacher would say, "I need an answer for these questions" and she would get a deafening silence. By the third term of Cameron in her class it was driving her crazy. She kept saying, "I am just not getting the answers I need as a teacher to support me." (Conversation, October 31, 2000)

The lack of support for Cameron's teacher was creating tension. You supported her concerns. You, too, felt there were insufficient resources to assist teachers. You questioned the role of different Department of Education staff and their ability to meet teachers' practical questions of how to include students. Sandi, you see the system as flawed. While the Department of Education had policy to support inclusion, resources were not available to help teachers be successful in including children. You pointed out that the teacher "was getting increasingly stressed by the lack of support and what inevitably happens is the child and the family bear the brunt of this frustration" (Conversation, October 31, 2000). You felt the lack of support for the teacher contributed to her suggestion that, for the next school year, Cameron spend the morning in a reception class, the equivalent of North American Kindergarten, and attend a combined Grade 3/4 class in the afternoon. You told the teacher you needed to think about it. You had learned over the years not to answer a question right away. Getting back to the professional at a later point was helpful. When you were ready to respond you were prepared to offer supports to assist the school in understanding your perspective.

> If I give you the research why you shouldn't do that (placing Cameron in the reception class) will you listen to it? They said, "Yes." So we had a sort of one off meeting and I said, "My position is really strong. I want Cameron to be included and these are the reasons why. I am offering you people I know that could come to the school and work with you. Will you have them?" They said, "Yes." (Conversation, October 31, 2000)

You set about contacting people in your network to see who could help you at the school. One friend suggested you contact Darrel Wills. When you did, he agreed to meet with the school. Darrel met with the teachers and the outcome was the teacher was angry with you.

> I don't think my teachers spoke to me for about six weeks after that because he actually gave them all the reasons why they couldn't do it. It wasn't what they wanted to hear. They were very angry. They had gotten a letter from me with a whole heap of recommendations from Darrel and what to do now. Then there was this big drama about how come the school let these people into the school like. How did they get in past the Department of Education? (Conversation, October 31, 2000)

Your relationship with the teacher remained disastrous and you wondered how the next school year would evolve. You did not waver in your decision that Cameron would not go into the Reception class in the morning. Cameron was to be promoted to the combined Grade 3/4 classroom full-time for the next school year.

Grade Three

Your university was very demanding and you stopped focusing on Cameron's schooling. You said you lifted your head up occasionally to see how things were going. Near the end of third term you noticed Cameron was still working on the same spelling words since the beginning of the year. This concerned you. You met with his teacher to express your concerns. Her response was he did not know the words yet. You challenged her and asked which other student had the same words for six months. You asked if she would be motivated to do the same thing over and over. To you it was almost "like they don't apply the same rules and principles of education to kids with disabilities as we do to other children" (Conversation, October 31, 2000). Cameron's Grade 1 and 2 teacher's knowledge was not shared with the Grade 3 teacher. You were once again in the position of having to work to educate a teacher on how to best support Cameron in an inclusive classroom.

Grade 3 continued to be a difficult year for both you and Cameron. You had increasing concerns with the program assistant. This concern was highlighted the day you picked Cameron up from at the after school care program and you learned he had been crying since he arrived.

> I picked him up from after school care and the coordinator said something is really wrong. Cameron cried the whole hour he had been there. We went home. He was really distressed and cried for another couple of hours. I finally made sense of what had happened. The boys had been away from school for a couple of weeks visiting their dad. Cameron was a bit nervous going back to school. It had been sports day. There was a sports day parade. The teacher aide must have gotten angry with Cameron for walking with his brother who is in a younger class. So she set him by the collar of his neck of his shirt and pulled him back to where she wanted him to stand. That totally undid Cameron. I knew that the relationship between these two was getting worse and worse. (Conversation, October 31, 2000)

When the after school care staff greeted you with the news Cameron had been very upset and inconsolable your concern that something was amiss at school increased. There had been warning signs things were not well between Cameron and the program assistant. That evening you worked with Cameron to build a picture of what had happened to distress him. You were concerned with what had happened and knew the situation was a delicate one and you had to address the problem with the principal.

> I needed then to think about how I was going to manage this. I talked to lots of kids in the class. I talked to some of the therapists that come in and do Cameron's speech. I got a picture that his teacher's aide had been obviously left to do the curriculum modification with Cameron. This was stressing her out because she had no qualifications. Initially she had been a very good supporter of Cameron. Obviously things had gone very wrong. (Conversation, October 31, 2000)

The program assistant had worked with Cameron for three years. She had been well supported by the teacher in Grades 1 and 2. In Grade 3 you felt this support was lacking and the program assistant was expected to plan and implement Cameron's education program. You had thought hard about how best to bring your concern, in relation to the incident during the sports parade, forward to the principal. You said, "I had to write a letter. I had to maintain the balance between complaining about what happened, putting safeguards in place for Cameron and saying she is not going to be there next year while keeping a relationship with school. It took me a while to figure out how to" (Conversation, October 31, 2000). In your letter you requested that Cameron not be left alone with the program assistant and that supports be put in place to help her with her assignment with Cameron.

You informed the principal of your concern about Cameron having the same program assistant for three years. You requested a male be hired to work with Cameron the following school year. You felt this would be a better match for Cameron. You told the principal that you would not return Cameron to school, in the New Year, if a new assistant was not hired and you would do whatever it would take to get a new staff assigned to Cameron. You wrote to the principal stating a new staff assignment was important to you. You wrote, "I believe after three years it is better Cameron has a new aide who will encourage his learning in a safe environment at the same time enhancing his image in the school community. I will happily work with you to achieve this goal" (Letter, September 15, 2000). When we had finished our research time together the school had not responded to your request.

Grade Four

Through e-mails you kept me updated on Cameron's progress in Grade 4. A male program assistant was hired. You e-mailed saying he was working out fine. The teacher and the principal were open to having Darrel visit. His visit was a great success. The teacher welcomed Darrel's ideas and the principal spent an afternoon meeting with Darrel. You were pleased things had improved and the staff had a new willingness to engage in the journey of including Cameron in the school. The transition was smooth and productive as Cameron began his fourth year of schooling.

Sandi and Valerie, your stories of your sons' transitions calls me to attend to the barriers you needed to overcome to secure and maintain inclusion for your sons. Your storied transitions are outside the boundaries of the dominant transition stories. School transitions are filled with uncertainty for all students and parents. Golan (1981) defined transition as "a period of moving from one state of certainty to another, with an interval of uncertainty and change in between" (p. 12). Uncertainty is inherent in transitions. However, your narratives expressed the additional uncertainty around your sons' continued access to inclusive education. Although you faced additional uncertainty and added institutional barriers, neither of you allowed this to deter you in gaining and maintaining inclusion for your sons.

This letter re-presented the telling of your experiences of transition on the school landscape. In the next letter, I explore your stories of the gazes you encounter from others, in relation to securing inclusion for your sons. These gazes attempt to story your sons in ways that are not the stories you wished to have constructed for them.

With Warm Regard,

Heather

CHAPTER VII

UNDER THE GAZE: THREADS OF TENSION

Dear Valerie and Sandi,

Sociologist Erving Goffman (1963), in his classic study on the stigmatized, asserts that stigma is socially constructed. Historically, stigmas were imposed on people in the form of marking or branding to discredit an individual. In modern society, however, stigmas arise through social processes of interaction whereby individuals are marked or segregated because of an attribute they possess that is perceived as negative. Goffman states that the stigma serves as a dominant status that determines the nature of the interactions the stigmatized person has with others accounting for the negative, prejudicial aspects of the reactions they receive because of their differences.

Disability carries with it a negative identity. Negative images of disability abound from media portrayals and legislature categories that often construct children with disabilities as dependent, vulnerable and "in need" (Priestley, 1999). These images of disability perpetuate disability as a negative attribute. Using the privileged discourse of normalcy, difference is stigmatized, contained and eliminated from the community rendering people with disabilities outside the boundaries, without power and voice (Corbett, 1996). Individuals with disabilities experience life on the borderland (Smith, 1999). This gives rise to a view that children with disabilities are different, require segregation from their non-disabled peers, and belong off the landscape of regular education.

A handicapping condition in North America is considered a stigma (Gadacz, 1994; Morris, 1991). Goffman (1963) asserts, "(b)y definition, of course, we believe the person with a stigma is not quite human" (p. 5). To have a child with a disability is considered tragic because having a child who is seen as less than human can only be tragic. This social construct (Corbett, 1996; Davis, 1997; Hanks & Poplins, 1990) of disability is not easily abandoned, not even when mothers' stories of their experiences with their children conflict with how society imagines it to be. When life experiences are shaped by a dominant social milieu that devalues and discriminates against people with disabilities, it is difficult to shake the effects of a society-wide structure of marginalization and discrimination. As parents of children with a disability, Valerie and Sandi, you have encountered the gaze of others in many ways as you feel them questioning your motives and doubting your perceptions of your sons' abilities and right to be included. It is has been difficult to work against the negative plotlines into which Jason and Cameron have been cast.

A Gaze From a Place of a Stranger

Sandi, while I was in Adelaide I took a weekend break from our work and set off to tour Kangaroo Island, situated off the mainland an hour drive from Adelaide and accessible by an hour ferry ride. My second day on the island, I went on a full day bus tour. Thoughts of our work filled my head until this point. I saw the trip as a break to rejuvenate myself before I tackled another week of gathering data and transcribing tapes.

When the tour bus pulled up to my hotel my head was filled with the thought of adventure. I left your words behind in Adelaide and on my computer in my room. I was out to see the wildlife that resided on the island. I was the first to get on the bus and selected the prime seat at the front. The bus driver greeted me warmly and said we would be collecting additional people en route to our first destination. The next passengers to be collected were two elderly women. We said hello as they selected the seat across from me. Throughout the morning we had fleeting conversations as we got off and on the bus between tour sites. In the conversations, I learned one of the women was a retired teacher. I thought, how small the world is to be sitting across from a retired teacher. I was to learn later that day that the world was even smaller.

At lunchtime, I joined the two women. In our conversation they asked, what was I doing in Australia? I told them I was working on my PhD. and had come to Australia to gather data on a parent's experience with trying to secure inclusive education for her child with a disability. Just as I finished sharing what I was doing, our conversation was disrupted. A koala was spotted through the window. This was our purpose for being at this location for lunch. The koala had come down from a tree and we all rushed to the window to see it move across the ground and travel up another tree. This delightful scene shifted our conversation away from my PhD. work to the koalas.

After lunch, we went on a walking tour of the grounds hoping to spot more koalas. I walked through the woods with the retired schoolteacher. As we walked, my companion said her daughter was a teacher. At the school where her daughter taught, children with disabilities were included. However, there now was a parent who insisted that her son, who is very disabled, be included. My companion told me that her daughter felt this parent was wrong to ask for inclusion and that the school's resources could not adequately support this student. The retired schoolteacher stated she had no difficulty with some children being included but not children like the one her daughter described. She asked me how I could be supportive of inclusion under such circumstances. I shared I was not in favour of poorly supported inclusion. I observed that adequate resources are not always made available to help teachers include a wider range of children. However, it was unfair to blame the children for the lack of resources by denying their right to be included. The matter of adequate resources needed to be addressed to help both students and teachers achieve inclusion. Our talk was again disrupted by our need to get back on the bus.

At our next stop, I asked the woman where her daughter taught. She told me the name of the city and the name of the school. Sandi, it was your school this woman was talking about. Cameron was the student she was referring to. You were the parent that insisted your child is included. Realizing the woman was talking about you, my head instantly filled with questions. How many schools are there in Adelaide, a city of over a million? How many people are teachers? How many teachers have parents who are retired teachers? How many people travel to Kangaroo Island in a day? How many people take the all day bus tour? What are the odds of meeting just this woman on the bus trip? Was this a coincidence or destiny? Was it my fate to experience this gaze on your behalf, to gain an understanding of how others story you and Cameron? This woman knew your circumstance, through the eyes of her daughter, even though you had never met.

This stranger's story confronted me. Her words and the conflict of being in relation with you created a dilemma for me. I was disturbed by the Kangaroo Island experience. When I encounter strangers' opinions in casual conversation, I usually try to listen and respond in a manner wherein I receive no criticism. I try to block my own thoughts and feelings. I respond this way because usually the topics do not effect me personally. This experience was different. Not only did I have something to say about inclusion but I also wanted to shout out to the stranger that she was talking about my research participant's son. The situation did not present itself. The bus arrived at my bus companion's hotel. I will not see this woman again but she will continue to story you as an unreasonable mother. I felt awful. I had not influenced her to think differently. I did not relish the task of sharing the story with you. I knew I must.

When I shared the Kangaroo Island story we were not having a taped conversation. We were touring the State institution for people labelled developmentally disabled with your colleagues from Independent Advocacy. When I told you the story you were quiet. I did not press you to talk. I was not sure if your quietness was in response to the Kangaroo Island story or the experience of visiting the institution, where over 500 people with disabilities lived in isolation. During our next scheduled taped conversation I asked you to tell me what you felt when I told you the Kangaroo Island story.

> Like I am the emperor with no clothes on. I am out there and in some ways it makes me more determined. … It feels like there are no shared spaces with other people. Sometimes it feels like there are no private spaces. (Conversation, November 5, 2000)

This is all you said. Our conversation moved to other places. When I returned to Canada I wrote you and asked again, how did you feel when I told you the Kangaroo Island story. You responded in an e-mail.

> I felt like the emperor with no clothes. My life is in public view all the time. Partly because I take a strong public stand, partly small town stuff. There is always someone connected to someone who knows your "reputation" as told by

> those telling the tale from their perspective. Pissed off that we are set apart by our difference, not by our sameness. Drained of energy that this will be our whole life story. But so stubborn that I will never give up and Cameron is my energy capsule. (E-mail, January 16, 2001)

As I began to write this piece, I e-mailed you again asking you to tell me how you felt when I told the Kangaroo Island story. I felt I was probing and worried that you would find my question intrusive. After all, I had already asked you to respond twice. I am not sure why I felt this way. You had been, and continued to be, generous of your time and thought as we e-mailed to each other since my return to Canada. I wondered if my unease had more to do with me. I wanted a deeper understanding of what you experienced. I felt dissatisfied in my understanding. When we were together I had not worked to gain this understanding. I was appreciative when you sent a response within a day to my question.

> I felt once again violated. I know in my head our life is public but in my heart I am still stung by the disrespectfulness of talking about people when you have no right to pass that information on. What pisses me off the most is that these people have no consciousness about their own stereotyping and prejudice. Usually they are the worst at being flexible and creative, accepting of difference and tolerant of people. Yet as a person with some power they are able to spread gossip about the intimate details of my precious, wonderful, inspirational, courageous son, in a negative discriminating manner grounded in the deep history of endemic discrimination over centuries against people with disabilities. It makes me despair that my work will never be done. I feel sick, paralysed, overwhelmed, and raped

> in a way that someone has invaded my most precious relationships with no respect for our love and value of each other. (E-mail, April 4, 2001)

Sandi, your final response helped me to understand how this stranger's story weaves within a matrix of storied influence over your and Cameron's lives. You see this stranger's perceptions as reflective of the historical negative attitudes that prevail towards people with disabilities and that continue to influence how we treat people with disabilities today. Allport (1979) argues humans have a propensity to be prejudiced, a pernicious aspect of a "normal and natural tendency to form generalizations, concepts and categories whose content represents an oversimplification of [our] world experiences" (p. 26). Shapiro (1999) asserts

> Unfortunately, the schools through their model of labelling and segregation, often provide the basis of negative attitudes. Students viewed as different are banished, denied access, and receive negatively loaded labels which, in turn, causes guilt, pain, and shame, not only for them but for their parents as well. Once labelled, they are treated as being somehow less than the others. (p. 9)

The stranger's account of her personal and social experiences of everyday life, her personal history, and social history on and off the school landscape show how she saw Cameron, a child who is different, as needing to be segregated for both his own good and the teachers' good. That Cameron carried the label, developmentally disabled, invited others to define what he deserved in school. Thus, Cameron was viewed through the lens of a label and the stranger did not seek to know Cameron, the individual. Nodding (1991) says, "(p)eople develop a moral orientation of caring, we suggest, through direct contact with those who need to be cared for" (p. 164). This stranger had not met your son. Knowledge of him would not influence her story of your son.

In your final response to my question of how you experienced the Kangaroo Island story, I gained a deeper level of insight into how painful this story was to you. When I asked how you felt the first time, I sensed there was more but did not have the courage to push to hear it. I now see that when you heard the story, you were left with one more scar, upon the many, that have been inflicted by those who carry historical negative images of children with disabilities, who do not venture to know Cameron, and who believe they know what is best for him.

A Gaze From a Place of Limits

Valerie, the gaze of others has often been in conflict with how you story your experiences as Jason's mother. The hurt, anger and strain you feel has not been generated by the conditions of having a child with a disability but by the gaze and resulting obstacles and offensive assumptions that society heaps upon you and your son.

> The most difficult, exhausting, painful thing is the energy it takes to educate people to treat him like a person. To see past what they think they see and to see what is really there. That is the hardest thing. It is ongoing and it never stops. That is what is stressful. It breaks your heart and breaks your spirit. (Conversation, June 5, 2000)

Valerie, you remind me of the power of the gaze of the professional and community in constructing children with disabilities as less than human and the cultural representation of disability as a 'personal tragedy.' I, too, encounter this attitude when I speak about inclusive education. The professional reaction to the notion of inclusion creates a tension that requires me to defend the idea that children with disability are more like their non-disabled peers than different and that our notions of disability and education have been culturally constructed. As an example, in a graduate level class when discussing my pending research on the narratives of mothers as they try to secure inclusive education, a fellow student asked if I was going to look at parents' denial about their children's disabilities. This educator expressed that parents' requests for inclusion was located in their denial of their children's abilities and if they faced the 'truth' they would see that separate education was most appropriate. As in this situation and in your experiences Valerie, others' interactions with Jason say little about what his life is and much about the professionals' and community members' attitudes towards Jason due to his disability. It is non-disabled people's feelings about Jason's differences that make his, and your attempts, to take his place within the world difficult and painful.

> Jason has never been the burden. It has always been trying to teach other people to treat him and give him the respect and love that he deserves. That is the burden. (Conversation, July 17, 2000)

While others may have seen Jason as a burden, you felt the burden of the gaze of others. This burden caused you pain and despair, and alerted you to the need to remain on guard to counter the dehumanizing attitudes others have about your son. Your experience of seeing Jason's strengths was denied in their gaze.

> It was just me that believed in him. I was the only one. I carried that. That was the burden, not Jason. I knew he could learn and everybody else's attitude was the burden. (Conversation, May 22, 2000)

For you, Valerie the power of others' attitudes forced you to challenge the standard representation of disability. Their gaze, as you say, is one that asks you to educate others to see Jason as a person. As Jason's mother, you worked daily to combat these views, challenging others to see your son as a valuable member of society.

A Gaze From a Place of Segregation

Valerie, you met a gaze of segregation in your contacts with Sharon, the district staff member who supervised programs for children with disabilities. Sharon did not support your request for an inclusive Kindergarten placement for Jason. Her gaze was constructed from what Clark, Dyson and Millward (1998) describe as the predominate paradigm of special education as being "psycho-medical." The key characteristic of this paradigm is a positivist view of special education in which the student's difficulties are objectively real and can be determined using methods of natural science. These differences are understood largely through the discipline of medicine and psychology, with a rationale that special education was a logical response to Jason's educational needs.

In the western world, two institutional narratives of schooling, the special and the regular, have evolved. Skrtic (1991a) maintains that throughout the past century general education and special education developed as separate but mutually reinforcing discourses in education. He argues that organizational policies and practices in both general and special education promoted the separation of regular and special education students and programs, and an elaborate system of assessment and classification evolved to support the need and management of these two separate systems of education. Skrtic

(1991b) contends special education in the 20th century is grounded in the assumptions that:

> (1) Disabilities are objective, pathological conditions that students have. (2) Special education is a rationally conceived and coordinated system of services that benefits students with disabilities. (3) Progress in the field of special education results from rational, technological improvements in diagnosis and intervention. (p. 20)

The first assumption sees disability as inherent in the individual rather than being inherent in the social context within which the deviance occurs. "The second and third assumption derive from the notion of organizational rationality which …assumes that the organizations are (or can be, if managed efficiently) as rational as machines and that changing them is a rational-technical process of fine tuning an existing machine (rather than replacing it with a new one)" (Skrtic, 1991b, p. 21). Sharon's views of what was best for Jason, and where to have his special needs met, originate from a view that sees the existing special education model of segregated classrooms as an appropriate response to placement for children with developmental disabilities.

Valerie, your desire for Jason to access Kindergarten in a regular classroom did not support segregated special education as a rational response to Jason's educational needs. You saw this placement as limiting and life defining. Your desire for an inclusive Kindergarten for Jason reflects the position of Clark et al. (1998), which rejects segregated special education as a rational response to meeting the educational needs of students with disabilities. Clark contends that the function of special education, as a social institution, has been developed to deal with school-generated failure. Segregated special education provisions developed as a means of managing this failure, thus creating structural social and socio-economic processes whereby some groups are systematically disadvantaged and marginalized. Since special education is not rational, and disability is socially constructed, then special education is part of the social construction that helps to perpetuate the social arrangement of the disadvantaged. Clark further asserts that, if educators accept the claim that special education is rational, then they are contributing to the sustaining of a system that is essentially discriminatory and oppressive.

Sharon's gaze of segregation determined Jason's school placement. Sharon's experience as a professional was taken as authority in asserting that Jason would be best served in a segregated classroom. The story of the expert professional, in a position of prominence and authority with access to knowledge and application of knowledge in a disinterested way (Skrtic, 1995), is prominent in Sharon's story line. This story line would have lead Jason to exclusion from an integrated setting, thus privileging segregated special education. You were not in a position of authority. You, and your son, were clients of special education. Sharon's professional gaze constructed a story that a segregated special education placement would be best for Jason. The emerging special education story line conflicted with your story of wanting Jason to attend his neighbourhood Kindergarten. It was only a change in personnel that paved the way for Jason to start his school career in a regular Kindergarten class.

Valerie, your stories of gaze from a place of segregation resonates with my hearing of Linda and Paul's story. They struggled with school personnel when Linda requested to have her son included. This was seen as outside the boundaries of choice schools made available to children with disabilities. Paul was disabled and, therefore, carried the stigma of 'other' and 'different.' This view of difference prevented school administrators from hearing Linda's request for it was outside the district-delineated view of available choices. Paul was disabled. Therefore, he was in need of a segregated education. As I listened to you Valerie, my thoughts often made me think how the threads unravelling in your story were also threads in Linda's story. Linda's story of asking nineteen principals to accept her son in a regular class comes to mind. Her request was denied because the professional gaze of segregation was prominent in responding to children with disabilities. However, if Linda had met a principal that would have allowed her son to attend a regular school, her story would have been different, just as yours and Jason's were with the change of personnel. The decision to be included appears to hinge on the good will of an administrator. Valerie, your storied plotline of securing an inclusive Kindergarten creates many questions for me and leaves me wondering what if the personnel had not changed?

A Gaze From a Place of Ability

Learning limitations began to be placed on Jason as he moved from Grade 5 to Grade 6. In response to Jason's behavioural outbursts, school personnel began to question Jason's ability to handle the academic material in the Grade 6 class.

> I very begrudgingly accepted her (Educational Consultant) recommendation. She had to do a lot of talking to convince me to let him go out of social studies and science. The plan in place was that he would go to the library and learn how to file cards and catalogue them on the computer, something very constructive, something that he could learn, that his mind was working at. That was the only way I agreed to it. I wasn't comfortable with it. It was one of those things where

> the dread settles in your stomach and it just sits there. You just know the wrongness of it. I could never admit to myself that this was okay or right but I let it happen because I thought he needed help. If somehow this could release the stress, maybe this is what we needed to try because the anger was just escalating. Then I discovered he was loading the dishwasher and wiping the tables in the staff room. This troubled me. I thought I would let this slide because maybe he just needed the break. You see he needed the break from his aide not from social studies and not from science. (Conversation, June 5, 2000)

Jason's perceived ability to learn was limited by the gaze that came from a story line that he was having behavioural outbursts because he was unable to do the academic work. The difficulties were seen to be inherent in Jason's ability, without consideration of the educational context in which Jason and his aide interacted. Valerie, you knew your agreement to have Jason pulled from academic subjects was wrong but you could not combat the professional view that Jason's outbursts were due to his ability and not the interaction with his aide.

> I didn't want him vacuuming because all of a sudden this is going to be a stereotype. In their minds they are going to think that this is all he can ever achieve, to push a vacuum. (Conversation, June 5, 2000)

Valerie, you struggled with what you saw to be life-limiting outcomes for Jason as the school began to construct a special education life skills program for him rather than an adapted academic program. You remained uneasy with your agreement to allow Jason to be withdrawn from academic subjects. When the agreed upon alternative of working in the library did not transpire, your unease forced you to question this expert professional determined decision. You confronted the school and challenged the teachers to reinstate Jason into the core subjects from which he was excluded.

> I went to his science teacher and said, " I have a problem with this and please tell me honestly what you think. Would Jason learn more sitting in your science class even if all he learns there is to sit still, to listen, to respect his classmates and his teacher or will he learn more loading the dishwasher and wiping the tables in the staff room?" He said, "Jason is back in science." Then I went to the social studies teacher who is also the vice-principal and I said the same thing to her about social studies. She said, "I don't know." I looked at her and said, "You have just lost all my respect. My son is going back into your social studies class so he can learn about Hong Kong. He can learn to sit and he can learn to listen. He can learn to respect you and his classmates but I have no respect for you anymore. I am sorry about that." Then I left. I went to the principal and said. "My son is going back into the classes." I was this woman that they blew into a major monster for court but that is okay. They wouldn't have done any differently if it had been their kid. (Conversation, June 5, 2000)

These continual confrontations to ensure Jason's needs were met were draining and demanding on you. Throughout Grade 6 you needed to constantly monitor Jason's program. You felt you could not place your trust in the school to do what was best for Jason, as you had when Sally was Jason's aide. As it seemed to depend on the good will of an administrator to allow Jason to be included so many years ago, I wondered if the assurance of receiving an adapted academic program was dependent on the skill of the program aide. Jason had been at the school for six years. Had he remained in the regular classroom because the aide advocated for this? Tensions between the institutional narrative of regular and special education appear to be at the heart of what was happening. Had the teachers always wondered why Jason was included? With the change of aide, were they now able to construct a life skills program for Jason, which they had always felt was more appropriate? Was the new aide the one who viewed life skills as more fitting? Had she changed the plotline for Jason and his learning? A new plotline was being played out when Jason's program changed from being focused on academic learning to focused on life skills. For you Valerie, the storied school landscape was shifting into dangerous territory. Jason was moving across the border into special education away from the inclusive classroom. As Skrtic (1991b) contends, special education was viewed as a rational service and Jason could benefit from it. Therefore, the school staff began to construct his education program to look more like a life skills program than an academic program.

Sandi, you too encountered the gaze of limitation in response to Cameron's educational needs.

> Some of the kids with disabilities at Cam's school go swimming on Monday afternoon. They say to me all the time that Cam should go. Cameron loves swimming. I think that is a really good idea but that is my responsibility not the school's. That is not education. (Conversation, November 17, 2000)

The attitude you encountered, that a swim program would be more worthy for Cameron than attending class with his peers, speaks to the devaluation others give to the worth of Cameron's education within the regular class. The two institutional narratives, regular and special were competing in the school's recommendations for the development of Cameron's education program. The school saw life skills as complimentary. You saw teaching life skills as interference to teaching what is important.

> They do not see that it is of vital importance for a person with a disability to read, write and have numeracy. It is important for every kid. (Conversation, November 17, 2000)

The gaze of limitations comes through the lens of the stereotypical view of what constitutes an education for a child with a disability. The stereotypical view is that children with disabilities need an educational program that is focused on non-academic activities for development of recreation, leisure skills and social skills and that students would benefit more from a functional life skills program than an academic program. You contested this stereotypical view and saw it as limiting, not enhancing, Cameron's learning. From your vantage point children needed to learn to read, write and compute.

The plotline that emerged from the disability landscape was a scripted story you did not wish for Cameron. However, the story of "swimming is good for the handicapped" lived side-by-side with your story of academics for all children. Not only did you encounter professionals trapped in the disability/special education plotline, you also encountered parents who were.

> He (principal) doesn't ask me as often as other parents of the children. I say I believe swimming is a family responsibly outside of school. I have that discussion with them. And it will be other teachers like Cam's teacher last year. And there was a release teacher in Cam's class for a while. Her husband had a stroke and she spent a lot a time at the pool with him rehabilitating. And she would tell me how wonderful it would be for Cameron. (Conversation, November 17, 2000)

You knew the story of special education, supported by an ongoing rhetoric of conclusions, would not stop. You needed to continue to defend your reasons for refusing Cameron permission to go swimming every Monday with the other children with disabilities. The school staffs' request to pull Cameron out of class every Monday created a discrepancy of expectations in your mind.

> In fact Mike (the school principal) wrote a note at the end of last term in the report card about how much school a child missed if you are ten minutes late every day. (Conversation, November 17, 2000)

The principal's notice that stated being late was counter productive to student learning created this discrepancy of expectation. The principal understood the behaviour of missing class due to lateness as harmful to student success but the message was inconsistent for children with disabilities. It was acceptable for youth with disabilities to miss an afternoon of learning every week to go swimming. You questioned why was your refusal to send Cameron swimming every week challenged and not why were children with disabilities excused from valuable academic instructional time.

A Gaze From a Place of Segregation Revisited

Valerie, as Grade 6 progressed, warning signs were beginning to make you fear that Jason's inclusion was under threat. Sharon, the district office staff, challenged Jason's right to continue on to Grade 7 with his classmates. Sharon's belief that she and the school system knew what was best for Jason, while expecting you to assume a deferential part in determining Jason's school placement was consistent with the story line you encountered when Jason first attended school. Sharon storied Jason's placement into Grade 7 as she storied it when he was entering Kindergarten. Valerie, you were awake to the need to counter the story line that professionals knew what was best for Jason. Sharon's story of what was in Jason's best interest negated, in your eyes, the successful inclusion Jason encountered until Grade 6. Sharon's gaze attended selectively to her professionally constructed story of Jason's needs and ignored your desire for Jason's continued inclusion with his friends. The professional gaze (Allan, 1999) of the dominant special education position was used to validate Sharon's subjective judgment about Jason and you, his parent.

> It (Jason's inclusion in Grade 7) was going to interfere with her plan and her program and no one was going to tell her it wasn't going to work. She wouldn't let anybody tell her. No one tried or they tried a few times, a couple of other thorns but she was able to brush them away and control their choices. Control their choices and control the Board. Ultimately because of that sequence of events the Board and Gary Mar (Education Minister) believed her expertise, her experience and her incredible position of control. She just expected that that would happen (Jason going to a segregated program) with us too. It would have happened to us too (if we didn't have help to appeal). I am convinced of that. (Conversation, June 19, 2000)

Sharon expected you to be a compliant subject. However, Valerie, you were unwilling to legitimize the professional gaze. You did not allow this professional to construct your son as an object of her knowledge. Sharon's perception of what was best for Jason, storied from her professional gaze, ignored your perspective. Sharon's knowledge of where Jason should be taught was located in a professional discourse. Valerie, your knowledge of what was best for Jason was located in your personal practical knowledge' through your day-to-day experiences and observations of your son's abilities and experiences in the regular classroom. The discourse of special education was stronger on the professional knowledge landscape and it was necessary for you to appeal Sharon's decision to place Jason in a segregated classroom. The appeal placed your family in a year long battle that weighed heavily on you, your family and those that stood by you and Jason.

A Gaze From a Place of Just Plain Unreasonable

Sandi, your narrative conveys that you felt others storied you as a parent who was unreasonable. Story fragments of how others viewed you appeared a number of times in the telling and retelling of your narrative. This feeling intensified after you refused to give permission for Cameron to attend the Kindergarten program in the morning and Grade 3/4 in the afternoon. You felt you were seen as difficult to deal with because you would not live the plotline the school staff scripted for you. When the school wrote Cameron's Negotiated Curriculum Plan (NCP is the equivalent to an Individual Education Plan) for Grade 3 you discovered they had written down every learning outcome and objective for Grade 3 students.

> They had a NCP meeting at the end of last year, because the dramas with Darrel, they thought I was this lunatic mother that wanted the impossible. What they did was a thing called, I am not going to remember the name, but it is the framework of education and they write down every single area in every single subject. (Conversation, October 31, 2000)

You felt the school staff responded this way as a reaction to your insistence that Cameron attend Grade 3/4 full-time. The teachers, rather than outline what would be reasonable goals for Cameron, presented you with the entire list of learning outcomes for students in Grade 3 as his learning goals for the school year. You saw this response as a challenge to your refusal to lay aside your desire to have Cameron included.

> I kind of got it in twenty pages (NCP). I thought brilliant! They just thought that I am just this neurotic parent. If anybody were reasonable they would have already gone to the special school. She is still here bitching about how the world goes and why can't you do this. What seems like logic to me seemed not at all like logic to them. I think we live in really different worlds. (Conversation, October 31, 2000)

The school staff's gaze cast you into the part of demanding parent. You felt no empathy, understanding or caring for your desire that Cameron remain included. Tension was apparent. The experience was annoying and pervasive as you tried to get the teachers to understand what you wanted for Cameron. It had been possible before when you worked together to achieve it. The hostile interpersonal communication that developed between you and the school was counterproductive to Cameron having a positive learning experience the next school year.

> I get quite frustrated about those kinds of things because I think they see me very much like a difficult parent who has huge demands, asking for things outside of what is reasonable. I expect them to teach my son, not just have him sitting in the classroom. (Conversation, November 6, 2000)

The gaze of you as difficult parent permeated your interactions with the school staff. The school staff's reluctance to view your requests as reasonable prevented the consideration or implementation of positive solutions. Open communication no longer occurred between the school staff and you.

The gaze of unreasonable parent was complicated when you were asked to sit on a MCEETYA – Ministerial Council on Education, Employment Training and Youth Affairs Task Force on Disabilities. Your appointment to this prestigious position understandably created dismay among the school staff.

> Then when I got put onto the MCEETYA Task Force that was a really interesting dynamic for the school. Suddenly they had this parent who had a say at this senior policy writers' table. I sit with the senior Department of Education staff in Canberra. There were interesting dynamics. How do you manage this person who is a resource outside of the school. (Conversation, October 31, 2000)

You were no longer a parent who made unreasonable requests but were now someone who could influence the policies that surrounded children with disabilities.

A Gaze From a Place of the Good Mother

Valerie, on countless occasions you were told, by strangers and acquaintances, how wonderful they thought you were as Jason's mom. These comments were disquieting to you.

> I used to get upset when people from the church said I was such a great mom.... At the end of that year he (educator) shook my hand and said what an incredible mother I was. I was surprised that I was anything great just being Jason's mom. (Conversation, May 22, 2000)

It took you time to realize why these remarks provoked anger in you. After all, those who said it seemed to think they were praising you for struggling against the difficulties having a child with a developmental disability must bring. When you unpeeled the layers of the comments, you realized that, at the heart of such remarks, lay the judgment that having a child with a disability must be awful, indeed, an intolerable burden.

> I just realized it a few months ago. They saw Jason as a burden and such a challenge but he never was to me. He is just my son. That is what he was. It wasn't hard for a mother to love her son. (Conversation, May 22, 2000)

For you Valerie, recognizing people looked at you and saw an existence, an experience they would do everything to avoid themselves, was disheartening. To you Valerie, you are and always will be just Jason's mom, a mom that loves this son no less than your other son.

> I am just a mother loving her son and expecting everyone else to love him the same way they would love any other kid or respect him as any other kid. I just assumed that they would and should and they better. ... Why am I such a great mother for loving my son? (Conversation, May 22, 2000)

Valerie, as the parent of a child with a disability, you experienced what Goffman (1963) calls the 'courtesy stigma.' A phenomenon of the gaze that not only judges the disabled individual as 'other,' but endows the entire family with a spoiled identity because they share a web of affiliation with the stigmatized. Valerie you are "normal," yet "different." You endure the burden of this gaze. However, rather than dissociate yourself from this affliction you seek to maintain a normal-appearing round of life (Birenbaum, 1970) by advocating that others see your relationship with your son is no different than the relationship all parents have with their children. You do not support the notion that your and Jason's relationship is different because he was born with a disability. Your actions and attitude challenge others in the community to recognize and regard your relation with Jason as no different than other parents' relationships with their children without a disability.

Valerie, your experience with comments from others, concerning your ability as a parent, makes me wonder why members of your community felt they had the right to make such comments. Do they comment on the parenting abilities of mothers who do not have children with disabilities? I wonder if these comments come from a culturally constructed image of otherness using the privileged discourse that difference is a stigma and should be contained and eliminated from community (Corbett, 1996). The power of expectations, roles and restrictions that society places on its members with a disability may be at the heart of the responses you encountered from community members because you chose to keep your son included in all aspects of the community rather than remove him from the public eye. Valerie, the stress you experienced through interactions with others in the community comes from your need to be regarded as more or less a conventional member of your community rather than a stigmatized member because your child has a disability. You and your family continue to experience this 'courtesy stigma' because of the view that the presence of a child with disability in a family deems such a family as abnormal and incapable of being effective (Faber & DeOllos, 1992). The fact that you were so effective as Jason's mother was counter to the social narrative constructed for parents of children with disabilities.

A Gaze From a Place of Being in the Public

Valerie, with making your dispute with the school board public, you exposed yourself to increased public gaze. This increased attention to you and your family added to the opposition you experienced in relation to Jason's right to remain in an inclusive education situation. Originally you only had the school board's opposition to deal with, but as you made your circumstance public, further opposition came from those that lived in your community. This included people you knew and people you did not know. Under this gaze of opposition Valerie, you struggled to find your way as you lived your life in the public eye.

> You feel like you are standing watching yourself having it happen to you. You feel your whole town isn't yours anymore. Like your house isn't yours anymore and you feel like when you are walking down the street everybody has an opinion. And it is not supportive. That is what you feel even though you know you do have supporters out there, even though you know people care and believe in you, believe in Jason. You feel when you are walking in town you feel like you are being judged by every direction even though people smile and say "hi" you know they are thinking, "Oh that woman, what does she think she is doing? Why are they doing that to their son?" You know that is what a lot people thought, that it was such a terrible thing. (Conversation, August 28, 2000)

Valerie, as part of making your appeal public you participated in forums to increase public support for your position.

> The talk shows where people were phoning in and saying that, you know a lot of them were very supportive. One guy phoned in saying his son or daughter had been in a class with a child that was very disruptive to the classroom. It was totally unacceptable. And he did not want it. The announcer addressed it immediately, very forcefully. Then someone else phoned in apologizing for that guy's attitude. I remember saying to them on the radio that he is just afraid. I was

> able to handle that because it was weeks later, maybe even months after one of the court cases or after something that was in the papers again. (Conversation, August 28, 2000)

Valerie, your ability to handle the public opinion varied as you encountered their judgments. At times you could respond with ease while at other times the stress was too much to handle.

> I was so angry with the letters to the editors. That stuff was so hurtful because they don't know us. They have no idea who I am and who Jason is and his abilities and his disabilities, either his limitations or his potential. They have no idea. (Conversation, August 28, 2000)

The public gaze came in different ways and in different forms. In a public place Valerie, you heard the judge, who was to hear your case in court say, your decision to pursue inclusion was wrong.

> We were at a restaurant and Paul said they are talking about your case. I said, "Who?" He said, "Right behind me, to my left. There is a man talking about your case." I looked over and caught this guy's eye. He was kind of dressed casual so I just assumed they were Board members. ... I remember his hand was sort of going up and down like it was driving a point home. I am sure he said this woman who refused to go the right direction or refused to do what the School Act, you know, what legally you know. I believed that it was this woman. It wasn't this family; it was this woman. He had made up his mind. That is why I thought it was a School Board member. He was adamant about this person not following the School Act. (Conversation, July 17, 2000)

Valerie, your struggle for your son's inclusion became public in ways you could not have envisioned. Your story of getting your son included in Grade 7 moved off the school landscape into the community. The risk of taking your battle into the community created further tensions as you encountered others storying you in ways you could not influence.

A Gaze From a Place of Church

Valerie, you faced reservations from your church congregation that your desire for Jason to remain included was the right choice. When you sought their support by asking them to pray for you, their gaze was doubtful that your desire for Jason's inclusion was right.

> Their questioning, their doubts about what we were doing didn't bother me because I knew it was the right thing. And I stopped worrying about convincing them and worrying about what they thought. (Conversation, July 17, 2000)

Valerie, you chose not to let their doubts stop you in your efforts to regain access to inclusion for Jason. Although you continued to request their help and understanding throughout the fall, you came to the conclusion you could not remain vigilant in requesting their support through their prayers. You finally came to the realization that you could not, and would not, convince your congregation that inclusion was the right choice for Jason. Valerie, you realized that when the congregation members said they would pray for God's will, this was sufficient. You knew God's will was to have Jason in a regular classroom with his Grade 7 peers.

> In January, I remember saying to them I could not do this if it was not God's focus. I could not do this without God's strength and courage. It would not be happening. It was like they were all sitting there and looking at me. That was when I realized that it doesn't matter what they think. I don't need to try and pound it into their heads. I don't need to do that. (Conversation, July 17, 2000)

As you came to this realization, you felt relief. You were on the right track, one that in your eyes was clearly directed by God.

> You know it was like it was almost surreal. I was watching them all watching me cry over this and dumping my heart at them and they are just sitting there with stone faces you know. So I thought okay I don't need this. I don't need to convince you because praying for God's will was good because I knew what God's will was. (Conversation, July 17, 2000)

Valerie, there was a common thread of rejection between your story and Linda's. When she sought support from her church community, she did not initially get assistance from her minister. Linda had not shared her conviction in God's ability to guide her in her struggle to have her son included with the support group. However, we knew her desire to meet with her minister and seek his assistance that the church was important to her.

Sandi and Valerie this letter presented the telling of your experiences of the gaze of others on and off the school landscape. In my next letter I shall explore your stories of advocacy to secure inclusion for your sons.

With Warm Regard,

Heather

CHAPTER VIII

ADVOCATING FOR INCLUSIVE EDUCATION

Dear Valerie and Sandi,

Like Linda in the first chapter, you both held a vision for your children, a competing story with the dominant social narrative of segregated education. You believed your sons deserved an opportunity to be full members of society. For you this included, but was not limited to, membership within the family, community, neighbourhood and school environment. For you, the dominant narrative of segregated education restricted your sons' rights to membership in the same groups as everyone else and limited their opportunities for self-fulfillment. You were aware the living out of the dominant narrative of segregated special education shaped situations which made it difficult for you to establish and live a story of inclusive education. Your passionate commitment to your sons' rights to be full participating members in society led to your emerging role as advocates as you worked to help your sons author stories of inclusion.

Your advocacy efforts were grounded in your beliefs in values such as acceptance, equity, access and opportunity. Your beliefs are expressed in a story of inclusion. As parents, you were aware you and your children were trapped in the dominant plotline of the social narrative where children with disabilities are denied the opportunity of equal participation in the regular classroom and are expected to attend segregated classes. Trying to live a social narrative of inclusion, segregated education was unjust and unacceptable to you.

In response to the recommendation of a segregated classroom placement for your sons, you both introduced the possibility of inclusive education. You interrupted the taken-for-granted plotline that children with disabilities were best educated in segregated classrooms. You acted to disrupt the story in progress, which professionals storied as your sons' education placement option, by advocating for inclusive education.

The construction of labelling categories used as a means to determine students' placement are, by definition, biased (Bishop, 1994). Bishop states a structure, which is socially constructed, can be socially dismantled, reinterpreted and reconceptualized. You worked to restory the dominant narrative that children labelled developmentally disabled are educated in segregated education by introducing inclusive education as an option because, to you, your sons' labels should have no bearing on their school placement choice.

Your efforts to prevent the taken-for-granted socially constructed categorization method used to determine where your children would be educated, could be viewed as a contribution to the community living movement. The community living movement reflects a growing understanding that the right to live a fully integrated life within the community, that is to live, to go to school, to work, to enjoy recreation and to be active in retirement, belongs to all (Porter & Richler, 1991). You contributed to the movement by saying "no" to segregation and asking for inclusive education (Gill, 1997). Following Gill's argument, you joined the movement the first time you said "No. No to our child having to live in a hospital, no to his being refused admission to school, no to the denial of medical benefits, no to separate classes, no to his being left off the team" (p. 246).

To make meaning of your stories as narratives of advocacy and its contribution to the community living movement, I turned to the social movement literature. I found it large and diverse. Within the literature, there are a number of opposing opinions about how social movements form. In different times and in different countries social movements were theorized differently. Social movement research of the 1960s and 1970s in the United States and in Western European countries speaks to how research took different directions.

In North America, the social movement research focuses on "resource management" and its variants (McAdam et al., 1988; Touraine, 1985) and on the availability of resources. It stresses the rational and organized character of social movement and the ways a movement creates interest and support for its goals. This is accomplished by looking at the costs, benefits and management of structures, strategies and efficient utilization and constitution of social resources. Research using a resource mobilization approach is useful when studying the life history of movements (Zald & McCarthy, 1979), for understanding societal support and constraints on a movement's organization (Tilly, 1978) and to make connections between the central political process of society and the social movement (Zald & McCarthy, 1979).

The European approach, called "new social movement" (Klandermans, 1992; Melucci, 1980; Scott, 1990), seeks to understand the new grievances and aspirations that are at the centre of social movements. As its central point of reference, researchers are interested in exploring the relationship between social movement and broader social change. The term "new social movement" was intended to make clear the parting between this movement and the institutional 'old' movements of the working class (Oliver & Marwell, 1992). Klandermans (1992) stresses that new movements differ from old movements in values, action forms and constituency. For example, the focus is no longer on an accepted premise of economic growth but rather on human rights. New social movements use action forms that are decentralized, anti-hierarchical and support direct democracy. Members of this new social movement are those marginalized by societal development and those sensitive to others' problems resulting from modernization. Class or rank cannot define this group because the problems they face are not limited to specific social division.

While reviewing the extensive research on the formation of social movements, I struggled to make meaning of how this research connects to our research. When I encountered the work of Kling (1995) I found a way to think about social movements in narrative terms. Kling argues social movements are constructed from identity-based narratives that vary within a common historical frame and are vital to social movement theory formation. These narratives reflect the way people make meaning of who they are and with whom they are connected. "Wherever they are, and whatever historical sources of their development, they are constructed from the interweaving of personal and social biographies – from the narratives people rehearse to themselves about the nature of their lives" (Kling, 1995, p. 1). He states "(t)he way in which collective action connects to the stories people tell themselves about who they are, and with whom they identify, is a process not well articulated by institutional theories of mobilization" (p. 3). He views social movement as essentially the social and personal narratives of the participants in relation to cultural narratives.

Thinking about social movements as forms of narrative does not discredit the impressive and extensive conceptualizations of collective action that have been developed. Viewing social movement as narratives is to see them as "experience-near." "It is a way of tying the abstraction and generality of formalized movement theory to the personal biographies of those who enact the movements. To seek the stories people are telling and listening to is to seek how they compose their lives" (Kling, 1995, p. 6). New narratives are always emerging. "There is no question: people will inevitably find stories through which to re-assert their presence and autonomy in the world. It is just that the stories they will tell, and the movements of resistance they will mold from them, will never quite take the form theorists and activists predict or expect them to" (Kling, 1995, p. 10).

Connelly and Clandinin's (1999) reference to the research of 1995 Nobel Prize winner, Robert E. Lucas, gives insight to why narratives of resistance and advocacy do not take the exact form social movement theorists predict. Lucas demonstrated economic futures are unpredictable because theories are constructed based on the belief people do not think and adjust spending decisions. Economic theorists assume individuals do not alter their behaviour in response to the situations they encounter. Lucas argues people change their practices as they think and interact within the economic conditions they experience. Therefore, economic futures are unpredictable. Kling helps me see this is also true for social movement theories. Social movements cannot be predicted. Social movements take new shapes and forms as individuals socially and personally interact within the cultural narratives of the movement. A social movement is shaped and changed as individuals participate in advocacy activities in relation to others. It is through studying the social narratives of participants in social movements that theorists can begin to understand how social movements are formed and created by the actions of advocates.

Sandi and Valerie, one way of thinking of your narratives of experiences was by seeing them as narratives of how you composed your lives as advocates for your sons. As

Kling suggests, you socially and personally interacted with the cultural narratives of a beginning social movement. You did not begin with the intention of being advocates. It was in living with your sons that you found yourself part of a social movement. However, your narratives help me understand how you each contributed to the community living movement. Your stories are "experience-near." They give a perspective on how you, as individuals, played a part in social change. Your narratives spoke of not only resistance to the taken-for-granted plotline that children with disabilities are best educated in special education classrooms but also to the plotline that parents cannot make a difference in a child's education. While you never planned to be advocates for the rights of people with disabilities or for inclusive education, advocacy became part of your narratives of experiences.

You each brought about change, in different ways, as you storied an inclusive education for your sons. Your collective stories illustrated there are many ways to be active in social transformation. Your actions were both formal and non-formal, from kitchen table meetings to community action. Contributions came from smaller, less visible acts to the 'grand' and more clearly visible acts.

ADVOCACY KNOWLEDGE

Sandi, your narratives of participation in advocacy spoke of a variety of experiences which helped you gain confidence and support. As you filled "your tank of knowledge," to empower yourself to live as an advocate, two themes emerged. These were "network of support" and "workshop attendance." These themes were a springboard to developing your advocacy skills and created a network of resources, both human and material, to help in your advocacy efforts.

Network of Support

Professionals

Throughout the years, you developed a strong network of support, which included other parents and community people. This network of people helped you develop a deeper understanding of your yearning for Cameron's inclusion. You gained energy knowing you were not alone in wanting inclusion for Cameron. Support for yourself through these networks, as you advocated for Cameron, came in many forms and from different places. You learned through the years there is strength, power and support in numbers. Whenever possible you worked closely with established groups and other parents in your efforts to secure inclusion for Cameron.

The network of professionals connected to Cameron's early education program helped increase your knowledge. Your relationships with these women gave you opportunities to exchange information, resources and ideas.

> A lot of the therapists involved in Cameron's early intervention team were wonderful women. There was this one woman who was just an inspiration to me. Her name was Jan. When our kids were in intervention settings, her practice was to challenge us about why we would make certain choices, to really get to the core of what you were looking for. Through her, I was absolutely crystal clear why inclusion and what it took. She always challenged my thinking. She lobbied me to be the president of a parent support group in the early intervention program. I kind of have this history of being involved in community. (Conversation, October 31, 2000)

Jan empowered you by challenging you to think hard about your choices for Cameron. Jan's challenges helped you to be an effective advocate and leader. The network of women under Jan's leadership acted as a support, and provided numerous benefits for you including helping to increase your personal strength, helping you break down system barriers, helping develop friendships and generating opportunities to guide others.

> I used to do a lot of talking of things through deeply with all the therapists to get a clear picture. They were some of the people that stood beside me in the whole context of getting inclusive education for Cameron. They wrote reports that took my view. They were powerful advocates. (Conversation, October 31, 2000)

The Early Education staff played a critical role in supporting you. The professionals responded with care and support helping you to develop a vision for Cameron that broke from the dominant narrative that children with disabilities go to segregated programs. These professionals helped you seek meaningful learning opportunities for Cameron within the regular school system. Together you worked to confront the taken-for-granted plotline of segregation. Collectively, using your relational knowledge of Cameron, you secured what you all viewed as the best educational option for him, inclusion. These professionals did not use their paradigmatic knowledge based on theoretical perspectives, within the culture of their professionalism, to create and maintain professional authority. They crossed a border, embarked on developing relational knowledge of your son while valuing your personal practical knowledge, helping you to secure an option that reflected your vision of community living for Cameron.

Parents

Sandi, you found it helpful to enlist the counsel of other parents. Contact with fellow parents helped you define your advocacy objectives, what you wanted to gain. Communicating with other parents in similar situations, contributed to the development of your advocacy knowledge. This network of parents who were telling and retelling their stories acted as a support by creating a connection between their narratives and yours. Their stories invited you to come and know the world of advocacy and your place in it as a parent. The parents' stories served an interpretive function, offering you instruction and techniques on how to gain successful outcomes for your efforts. Hearing their stories helped you to see, as a parent, you could effectively be an advocate and change Cameron's school placement option.

> My friend in Queensland, who is this wonderful gorgeous person I love to pieces. She knows more about the education department policy than the department knows about their policies. She is wonderful. Her daughter has just finished school. She went all the way through regular school. My friend is a very centred, calm woman. She would go to her meetings and would say what she wanted up front. Then let everybody talk for hours. Before they left, she would say, "Could we now get back to my point?" She would always win. It was great. It was fantastic. I would ring her all the time and say, "What do I do here?" (Conversation, October 31, 2000)

This parent's personal strength and resources to move an agenda in her favour were a welcomed source of support. Her stories both called you to consider what you knew and to explain how to proceed. In listening to her stories, you were motivated to seek your desire for Cameron to attend the neighbourhood school. This friend played a critical role in supporting you. Her accomplishments gave you the courage to face the barriers and reach your goals for Cameron's schooling.

> Because I was part of QPPD I heard some wonderful stories of other families and friends. That just inspired me to never give up for Cam. (Conversation, October 31, 2000)

Your membership with QPPD brought you in contact with other parents who were pursuing inclusive education for their children. These relationships increased your confidence and gave you a sense of control over your ability to shape Cameron's placement choice. Being surrounded by parents telling and retelling their stories of shared beliefs and placement preference contributed to your strength to endure the challenges you faced.

New Beginning

Your network of support changed when you travelled to South Australia. Not only did the move create turmoil within your and the boys' lives, you also left a support network of friends and professionals. Your participation with QPPD and CRU had been positive. Once settled in South Australia, you joined a similar group called Independent Advocacy (IA). You shared, "Independent Advocacy is seen as the organization that is really strong in South Australia. I am the chairperson" (Conversation, October 31, 2000). Involvement in IA helped you to develop a new network of professional advocacy staff and parents connected to the organization. Through your association with QPPD, CRU and the professionals from the early intervention program you understood being part of a network of people, who shared your beliefs, was important.

Being connected to IA, you gained access to valuable resources and support. However, you knew the network in South Australia was different from the Queensland network.

> The people that supported me in Queensland, a couple of them have become close friends. Cam's speech therapist continues to be a good friend of mine. Every time I go back to Queensland, I am just welcomed with open arms. People there are really close to me. I would have stayed involved in QPPD. I would have had that really strong community of strong advocates and voices. The support I get here is different. I have been thinking about that after going to Stratmore (the state institution for people with developmental disabilities). I came away thinking I have to build a better circle of friends for Cameron. That needs to be some of his school friends and some of my adult friends. (Conversation, November 17, 2000)

The Queensland network developed into friendships which provided a sense of a long-term commitment to both you and Cameron. The visit to the state institution awakened your fears and concerns. Cameron was vulnerable because of his disability. In order to safeguard him from an institution you realized you needed to strengthen your network to ensure Cameron's safety.

Attending Workshops

Sandi, your association with QPPD and CRU was critical to why you chose inclusive education for Cameron. Hearing speakers talk about positive perspectives of inclusive education framed what was best for Cameron.

> They (CRU) had a series of paper bag lunches. One of the days was on inclusive education. I was just at the beginning of being ready to deal with the school

> system at that point in time. I went and Roger Slee did this wonderful talk about inclusive education. At question time, I said, "That is great Roger. I really want this but how do I get it." He said, "You need to talk to QPPD." (Conversation, October 31, 2000)

Hearing an Australian educator present inclusion as an option clarified, for you, what school would look like for Cameron. This session was one of many you attended. Attending sessions, hearing stories of supporting and achieving inclusion, strengthened your resolve that inclusion was right for your son. Your involvement in QPPD exposed you to international speakers who presented the status of inclusion in other parts of the world.

> QPPD in the 80s and early 90s spent a lot of its funding to get international speakers over. So Marsha Forest and Jack Pearpoint, Tom Elkinds and Darcy Elks came and spoke. This kind of leader of the world spoke on behalf of QPPD. (Conversation, November 5, 2000)

Hearing international speakers added to your knowledge and reasons for seeking an inclusive education for Cameron. The beliefs the speakers expressed contributed to your creation of an understanding of what inclusion looked like for children with disabilities. Your participation in the speakers' series was informative as you composed your vision for Cameron. By attending these sessions, you embarked on a journey of self-education preparing you for the advocacy role you needed to assume to get Cameron into a regular school.

We learn by both hearing and telling stories. The narratives you heard through the networks and sessions you attended invited you to come and know the world of inclusive education and Cameron's place in it. The stories you heard were powerful in building your personal practical knowledge and your paradigmatic knowledge on how best to gain inclusive education for Cameron.

ADVOCACY AS EDUCATING OTHERS

Sandi and Valerie, part of your advocacy efforts to promote inclusive education was to educate others. Sharing stories of your sons' lives, your experiences with advocating for inclusion, the hardships and victories you encountered was important to you. Through the telling and retelling of your stories, you saw that others pictured the barriers your sons and others with disabilities faced each day. The barriers they faced included exclusion from a regular education, negative and discriminatory attitudes and unsupportive government policies. You used every possible opportunity to educate others about the societal barriers your sons faced and how you, as their parents, worked to overcome the barriers.

Educating Through Story

Valerie, the telling and retelling of your story was central in your advocacy efforts. The stories you shared were your stories as Jason's mother. It mattered to you what story you authored with your son. The institutional narrative of segregation was not for Jason. You worked to construct a story of inclusion with your son. It was this story you used to help others see different possibilities.

The telling and retelling of your story was your way of advocating for Jason. You used story to represent your lived experience. You shared stories of your experience of parenting a child with a disability. Within your numerous contexts, from the hockey arena to the legal depositions, you told your story as Jason's mother.

> I was just a mother. I was just being Jason's mother. That is all. (Conversation, May 22, 2000)

This story was your story to live by.

Your advocacy story, constructed as a mother's narrative, emerged from the landscapes of home and community where you worked to construct stories of inclusion. In the telling and retelling of your story to live by, you had a sense of awakening to yourself as a knowledgeable person. You realized your personal practical knowledge had a place in shaping the landscape of education. You persistently shared your narrative as a means of influencing and educating others.

Your story illuminates the importance that telling and retelling a story plays in advocating for change. You used stories as a tool to persuade others in your efforts to secure what you needed. You wrote your story, as well as told your story, as you advocated for Jason.

> My letter to go to the board, it was too long but I thought I couldn't change this because it says everything and everything is so important. I cannot change this. (Conversation, June 19, 2000)

There was strength in the way you told your story. The story illustrated relational knowledge of your concerns. Your personal testimony created a picture of a living boy. You believed others needed to hear and validate your relational knowledge of Jason. The heart of your advocacy was your story. You were empowered through this advocacy approach.

The power of telling and retelling your story became evident when I heard a professor, who shared in a discussion group I was part of as a graduate student, about his experience of having you as a speaker in one of his university classes. He told the group how your story of advocacy had an impact on the students. Your narrative knowledge, which was embodied and personally and socially constructed, was different from the knowledge these students had about children with disabilities. The university students' knowledge was received and procedural, connected to the institutional narratives of archaic attitudes towards individuals with disabilities (Patton, Blackbourn & Fad, 1996). Your story forced the students to consider what they knew and to help them reflect on their socially constructed belief that children with disabilities belonged in segregated classes. These pre-service student teachers were caught in the plotline of special education as currently structured, a plotline in which students with disabilities must be given negatively loaded medical type labels (Shapiro, 1999) and be segregated. Your story helped these teachers gain narrative understanding of your and Jason's lived experiences and created new possibilities for the children and youth these teachers may encounter in their teaching career.

I too have heard you speak to educators and other parents. I heard you explain what happened, describing events in chronological detail. People seemed to need to hear your story out loud so they could make sense of what happened and what is going on now. "You are like a spider, your words the filaments of sound, lines you are spinning to attach the web of your experience to a corner of the world. In this way you connect the thin gauze ..."(Gill, 1997, p. 24) to the people who sat mesmerized by your story. You held them captive when you told your story of your experiences as a mother of a child with a disability, a story different from the one constructed by the social narrative. As a parent, you understood Jason's disability is not who he is; you understood his mind is not his soul. The listeners confronted their preconceived ideas and were forced, as they listened to you, to look at the deeply embedded socially constructed view of disability.

Educating University Colleagues

Sandi, your personal outlook on the value of your son, contributed to the importance you gave to every situation as an opportunity to educate others. A university assignment created a space to educate classmates about your son's right to an inclusive education.

> In a Social Policy Analysis course one of our presentations had to be on a subject we were passionate about. We had to make a recommendation to a social justice committee. A friend and I decided to talk about the history of disability. That was our passion. Then we got four other people in our group that were sort of loosely interested in disability issues but certainly not the passion having a child with a disability makes. (Conversation, October 31, 2000)

The additional group members' quasi interest in issues related to disabilities concerned you. You felt the new members did not carry the passion you had as a parent because they did not possess your relational knowledge. You would not allow their lack of passion to limit the importance of this course exercise as an opportunity to educate others. In trying to agree on a focus within the topic of disability, the new members presented an idea.

> They decided we were going to do the day in the life of a person with a disability. We will do a story about a woman with a mental illness who had her children taken away. I said, "You can't do that." I said, "Did you for one minute stop and think about all the stereotyping you have just done in one single statement?" I am

> not very good at being quiet. I said, "You have just fallen into the trap of assuming because she has an intellectual disability she cannot be a parent." I said, "I could actually take you to friends that are fantastic parents and who have mental intellectual disabilities. So no, we are not going there." (Conversation, October 31, 2000)

You did not remain silent in response to an idea that, in your opinion, viewed individuals with disabilities in an unfair light. You willingly embraced conflict and risked division in the group to explore an understanding of the experience of individuals with disabilities. Your refusal to agree forced the group to pursue an alternative focus. The decision that emerged was each member would take an area of social policy and present how the policies effect individuals with disabilities.

> We had a meeting in our semester break. The guy doing education said, "I can't find any research on inclusive education." I said, "Wow, that is a really powerful statement because we are sitting here in a university that teaches teachers." How come you can't find any inclusion information?" He said, "I never thought about that." Then he went on about how he didn't think he would send his children to a school with kids with disabilities. I said, "I will have that conversation with you when you have knowledge about it. I am not prepared to discuss why I send my son to a neighbourhood school." I said, "If you need some research material, come to my house. I will give you some because I have heaps." (Conversation, October 31, 2000)

You witnessed on this occasion, as you so often experienced, a fellow classmate making judgments of people with disabilities based on limited knowledge, be it paradigmatic or narrative. You were not tolerant of claims that were not well thought out or based on inaccurate information. You used your knowledge to guide your colleague to acquire meaningful understanding of the experience of individuals with disabilities. With access to many resources, you were a source of information. You offered to assist your classmate in expanding his knowledge.

> The fellow doing education came and said, "I can't believe I used to think that way." Good! Only one person got the main message that disability has been created by society. It doesn't actually belong on the individual. If you get born with a label, you are stuck with it because society defines you that way. It is irrelevant to you as a person. It was an interesting journey. He actually said, "If you had not been there, I would have learned nothing. You know I am glad that I learned so much." I am glad he learned it too. (Conversation, October 31, 2000)

You were confident in your ability to raise concerns constructively with fellow students. Your confidence in your ability to advocate contributed to changed attitudes.

Your efforts to educate others were central in all your interactions with individuals on campus. You not only focused on educating your fellow students but also aimed your advocacy efforts at course instructors.

> I am a very vocal student at university. I think sometimes tutors and lecturers really hate me. I see my time at university as a time of teaching other people about bigger issues. Like the tutorial group, I saw that as a window of opportunity to influence. (Conversation, October 31, 2000)

Your personal practical knowledge, as a parent of a child with a disability, and your work in educating yourself about inclusive education were woven into your daily interactions with lecturers. University was one place where you shared your knowledge in order to dispel negative notions people have about people with disabilities.

Educating Other Parents

Sandi, as a component of your university studies, you did a practicum placement with Independent Advocacy. Because you knew many children with disabilities were not accessing the regular education system you focused on helping parents see how the existing education system was designed to segregate their children with disabilities.

> I did a full-time placement at Independent Advocacy. I took on the role of advocate for other parents. That was a really good year for me doing advocacy for other families and spending time with other parents. I ran workshops for parents on why you would choose to include your children. (Conversation, October 31, 2000)

In your practicum, you understood the importance of assisting parents in making informed decisions about where their children would attend school. You were aware it was necessary to orient parents entering the school system in early education programs to understand why they might want inclusion over a segregated option. When you sent out your workshop flyer to parents in early intervention settings, a segregated special school sent you information about their program.

> The special school, I am always under pressure to send Cameron to, sent a flyer about their program and said, "I am sure you will need this because you will need to tell parents about the other options." I didn't know if I should get hysterical about it or just ignore it. It is crazy making. The flyer was beautiful. I think there

> is a real lie in special education. It needs to be exposed. The lie is that kids are not safe there most of the time. (Conversation, October 31, 2000)

You were frustrated by the biased options parents were offered by the system. When you created an opportunity for parents to dialogue about a different option (inclusive education), you were confronted by the power of the taken-for-granted plotline that special education was the best choice. You were aggravated because you felt the slick advertisement prepared by the special education school worked to entice parents to choose this option. You hoped your series of sessions would attract parents whose children were in early education programs so you could dispel what you saw as the "lie" of special education.

> When I did the course, I sent out 200 flyers to families in early intervention settings to come to the workshops. I thought we would be lucky if we got twenty parents. We ended up getting a whole heap of parents whose kids were school age and who were struggling having their kids remain included, while only one woman attended who was looking at trying to get inclusive education for her child. (Conversation, October 31, 2000)

You had not reached your target. You hoped to encourage parents of young children to choose inclusion over segregation as their children entered formal schooling. Although you were discouraged because your efforts did not reach the parents you targeted, your course helped a group of parents whose children were already included in the regular classroom. Your work shifted from helping parents to create the vision of inclusion to encouraging the parents in attendance to build alliances within a broader parent constituency as they worked for continued inclusive education for their children.

SYSTEM ADVOCACY

Sandi, in securing inclusive education for your son, you felt what you achieved individually would not be guaranteed in the future. You were aware other children in your community and in other communities did not have access to inclusive education. This bothered you. You felt it was important to use the current system to get what you wanted as well as to change the system so it served both your child and other children in inclusive environments in the future. To accomplish change, you worked in different ways to influence the systems connected to education.

Government Committees

Sandi, in order for the rights of your son to be fully recognized, you understood the need to advocate for change in government policies and legislation to incorporate issues about inclusion in the central design. Your efforts to do system advocacy led you to being a representative on both State and National government committees. You were a representative on the Ministerial Council on Education, Employment Training and Youth Affairs Task Force on Disabilities (MCEETYA), as a representative from the disability community. The work of the task force was to review the Disability Discrimination Act (DDA) in relation to education for children with disabilities. You found your involvement in this committee to be a form of tokenism.

> The other thing that happens in education is tokenism consultation. The MCEETYA Task Force is a good example. There are two representatives from the disability sector for all of Australia. We sit with twenty-seven senior education bureaucrats. We have this much voice. These bureaucrats come to the table. The DDA says the goal is to eliminate discrimination. The people from the

> department come and say how can we reduce the number of complaints, not end discrimination. (Conversation, October 31, 2000)

You were frustrated that government representatives were primarily concerned with decreasing complaints rather than looking at the systemic biases that contributed to discriminatory actions towards children with disabilities. Reducing the number of complaints did not ensure the policies supported inclusion. You were aware the DDA, which appeared to be a progressive law, did not guarantee inclusion. You saw the need to monitor the impact of the current policies and practices to bring about change in relation to service provisions to children in regular classrooms. To you Sandi, the senior government staff's desire to decrease the complaints was a simplistic measure in complying with the DDA. While you wanted senior bureaucrats to understand the intent of the law, the meetings were not designed to encourage a meaningful dialogue.

> Because we can't even have real conversations, we have to have this pretend stuff. Like when I sit with these bureaucrats around the table at MCEETYA. We have pretend conversations. We can't even talk the truth. When you can't talk the truth how can you change? When I say, as a parent, this is irrational. They don't want to hear it. They know it is true but they don't want you to talk about it in a public place. (Conversation, November 17, 2000)

When you brought issues forward, which you saw as meaningful for both Cameron and the families you represented, your input was not welcomed.

> Inclusion is not even in the conversation. We went to one standards meeting where we were talking about participation for children. We said, "No we want inclusion here. We don't want to participate. Participation does not guarantee full

membership of the social, curricular, physical environment in the school. It has got to be inclusion." The guy from New South Wales said, "We are not writing that. We won't agree to that because if we put the 'I' word in there we will have teachers' unions on strike around the country." (Conversation, October 31, 2000)

Sandi, much was at stake for you. Your passion as a parent was the impetus for action. Your determination was part of your reason for staying on the Task Force even though you found it frustrating. The Task Force work was one of many advocacy efforts that consumed your time. Your work on the committee was not rewarding but you remained involved because, as you said, "I wouldn't have it any other way because he (Cameron) is my hero. As long as he can get up in the morning I can stand beside him" (Conversation, November 17, 2000). Your work in the government arenas was instrumental in helping you to understand that laws and policies did not truly support inclusive education. However, you were prepared to lobby as many people as you could to create pressure to secure quality education not only for Cameron but also for all children.

SHAPING THE MOVEMENT

Valerie and Sandi, your narratives of experience show many ways parents are advocates. Whether as a part of an organized national association or working alone at the neighbourhood school to improve things for your children, you are involved in a social and political process. Your narratives show that parents who advocate in big and small ways for their children with disabilities can influence their children's education options.

As advocates, you both gained a sense of solidarity and consensus that extended beyond your individual circumstances. Your personal lives were transformed through your individual actions, and, as you changed, you changed society. You both developed a sense of purpose and awareness of your strengths because of your advocacy efforts.

There was much you did to promote inclusion and your ideas of what was good for your children. The more you knew, the more you were both able to make your own cases for why inclusion was right. You worked to help educators and others understand what you wanted and how it was possible to get it. You were able to individually and collectively sharpen your vision, educate yourself and gain knowledge on how to achieve inclusion for your sons.

In my final letter in this inquiry of making meaning of your narratives of advocacy, I write a reflective letter to you on how listening to your narratives and making meaning of their storied effect on my journey as an educator awakens in me my responsibilities to hold your stories dearly in my role as a school principal.

With Warm Regard,

Heather

CHAPTER IX

MAKING SENSE OF PARENT STORIES

Dear Valerie and Sandi,

As I come to the end of my narrative inquiry to gain an understanding of, and to make meaning of, your narratives of experience in securing inclusive education for your sons with developmental disabilities, your stories reside within me and I feel a responsibility to hold them dearly. Lopez's (1990) storybook "Crow and Weasel" speaks to the sense of responsibility I feel. In his book, two characters, Crow and Weasel, set out on a journey. Along the way they discover their spiritual relationship to the land, learn respect for others' traditions and learn responsibility to one another. On their journey they meet Badger who tells them

> The stories people tell have a way of taking care of them. If stories come to you, care for them. And learn to give them away where they are needed. Sometimes a person needs a story more than food to stay alive. That is why we put these stories in each other's memory. This is how people care for themselves. One day you will be good storytellers. Never forget these obligations. (p. 48)

As I listened to your narratives and reflected upon how I make meaning of your narratives and their affects on my journey as an educator, I was awakened to how I must take care of your stories and my obligation to tell your stories of inclusion. Your stories are connected to me. Your narratives help me to understand my responsibility as an educator. They move forward within me and are now part of my story of inclusive education.

Stories motivate me. When I know something in an abstract way, I am not motivated to act in the same way as when I hear a story. Your stories taught me and have been a powerful tool in helping me, as an educator, to reflect and restory my knowing of children with developmental disabilities. They have helped me to further construct my responsibilities as an educator in response to parental requests for inclusive education for their children. As Lopez says, your stories help me to stay alive, to care for myself as I continue to find my place on the school landscape.

As I moved from being a graduate student to the school landscape as principal, I carried your narratives within me. I write this last chapter from a shifted position, as school principal. I returned to the school landscape with two years of listening to your stories and writing the narratives of experience of your efforts to secure and maintain inclusive education for your sons. I had written, read and reread your narratives as texts from which I recovered meaning and learned something about "what I know." My stories of advocacy for inclusion, living alongside your stories, have shifted my knowing. What I know now has been shaped by who you are, what you know and how you know it as much as it is by who I am and how I know. This restoried knowing resides within me as I returned to the school landscape positioned as school principal.

I wondered as I returned to the school landscape how I would live in changed ways? How would this restoried knowing be experienced in my shifted position as school principal? How would this restoried knowing bump up against the social narrative of the institution that I returned to? How would I create spaces for parents of children with developmental disabilities, parents whose stories might resonate with yours? With this restoried knowing, I examine the tensions and dialogues that may arise in my shifted position as a principal as I bump up against the social narrative of segregation constructed for children with developmental disabilities.

Stories to Live and Work By

The Answer Is ...

I encountered, earlier than I thought, an understanding of how your stories would shift my response to the inclusion of children with developmental disabilities. Weeks before school was to start, I learned about a student with a developmental disability that might, potentially, attend my school. The student had been directed to a special education class in June for the upcoming school year. However, her parent had not filled out the necessary papers to secure the placement and had, as a consequence, forfeited the place in the special education classroom. The principal of the school, to which the child had been directed, called to alert me of the matter. The student resided in my school residency area. The principal of the other school pointed out it would now be my responsibility to secure an "alternative placement" for this child as the school district policy stated. In the mean time, I would be required to provide a spot at the neighbourhood school until a district site was located. The neighbourhood school was seen as a place of waiting, not a place of being for this child. I had yet to meet the child or her parent. I knew only that she was disabled and her parent was now being directed to speak with me to assist her to secure a school placement for her child. I recognized the professional gaze constructed a story that a segregated special education placement would be best for this student. I felt your storied presence as the situation unfolded.

On the school landscape, placement decisions for students with disabilities are constructed from the authority of professional knowledge. This paradigmatic professional knowledge of student placement decisions is based on a theoretical perspective within the culture of professionalism. It creates and maintains professional authority and contributes to the separation between professionals and their clients in determining decisions of school placement.

Being mindful of how living alongside your narratives of experience, Sandi and Valerie, had shifted mine, I did not wish to use my paradigmatic knowledge based on theoretical perspectives within the culture of my profession to create and maintain professional authority. I wanted to develop relational knowledge of this child and seek this parent's personal practical knowledge to determine how to help this mother secure an option that reflected her vision of what education should look like for her daughter. The dominant social narrative for children with developmental disabilities, on my current school landscape, is they are educated in segregated special education classes. Holding your narratives in my mind and body, knowing you would want me to have relational knowing to understand the plotline this parent wished for her child, I waited to hear her desires. I wish to share authority (Oyler & Becker, 1997) with this mother in deciding what this child's education placement would be.

I waited in anticipation for this family to appear. Prior to their arrival, the school secretary informed me the child with the developmental disability had siblings that attended our school and the child with the disability had been at our school last year and had been sent to a special education class, at another school, mid year. I began to know a story of this family before they knew a story of me. I heard how they were storied and saw the gaze of others questioning this parent's motives. Last year they lived the dominant story of segregation. Holding your narratives in my mind, I wondered, "What was this mother's story?" I wondered, "Why had she not filled out the forms to secure the special education placement for her daughter?" I knew from your stories that the parent had a story. I wanted to listen to her request for her child's school placement, to discover her story as new. I did not want to hear this mother's story through the gaze of the dominant social narrative of segregation. I wished to hear her story, as you both would want me to.

It was days before I finally met the family. The mother came the day before school was to start with three children in tow. She said she wanted to register her daughter who attended a different school last year. The mother made no reference to her child's disability, although upon meeting her it was apparent her daughter had a developmental disability. I sensed this mother's urgency and apprehension as she asked to register this child at our school. Valerie and Sandi, I was mindful of your narratives of experience of registering your sons at the neighbourhood school as I responded to this parent's request. I imagined you sitting before a principal, a principal who was now me. I invited the mother to sit in my office and told her about the call from the principal from the school where her daughter was to attend this fall. I told her the placement had been forfeited. The mother responded, in a matter of fact way, that she wanted all her children to attend the same school. After visiting the special education class she felt her daughter would do better at this school. She did not use the word "inclusion". She just quietly said she wanted to register her daughter here because her other children attended this school.

The power of this mother's convictions as she sat in my office, the urgency I heard in her voice, the tentativeness of the response she thought she may get from a stranger, transported me to a world where hearing parents' stories matters. I knew I must take care of her story. The power of her personal practical knowledge of what was right for her daughter was clear. The few words of her narrative captured the emotional struggle embodied in her words. I heard your narratives, Valerie and Sandi, as I responded unequivocally that her daughter would be granted the opportunity to attend school with her siblings. I would not seek an alternative placement because this is not what she wanted. As Lopez reminds me, your stories cared for me, your stories provided me the substance to respond to this parent.

I knew the hierarchy of status and the place of privilege of principal on the landscape of school. I responded to this parent from a different plotline, not from the traditional place of professionals who control educational decision-making. In part, I learned this from your narratives of experience. My response provided this parent a space for her voice in the dialogue in her child's education. But I knew, on the landscape of schools, I held the balance of power in allowing her to shape her child's educational experience. And I wanted to work to create a different place, a place of shared authority. Your narratives accounts lived within me as I sat with this mother, and hearing her narrative, I believed the neighbourhood school was the right destination for this child.

Supports: Learning From Experience

Sandi and Valerie, your narratives highlighted the importance of a principal's attention to the supports needed for the successful inclusion of children with developmental disabilities. I needed to address this to ensure this student succeeded. As I talked with the parent, I told her we would work to develop a modified program to best meet her daughter's needs and that I would need to seek support for the teachers and provide adequate assistance for the child. This was my responsibility. However, I felt it was necessary to share with the mother what needed to be in place to support both her daughter and her daughter's teacher to ensure a successful year.

Being new and unaware of the school staff's skills and abilities, I pondered how I would respond to the matter of support for the teacher and assistance for this student. This has been an evolving process as I work with the teacher on a weekly basis to hear her concerns, seek resolutions and gather the supports she needs to help the student be successful.

The teacher questioned, two weeks into the school year, if I was seeking a segregated placement for this student. The professional gaze constructed a story that a segregated special education program would be best for this child. The story of inclusion is a competing story on my current school landscape. It is not the dominant story. As principal, I live on this landscape. As teachers, we have learned to live in, and to feel comfortable, in the plotline where children with developmental disabilities are best taught in segregated settings. In my need for others to hear, and validate as knowledge, parents' personal practical knowledge of their children, I worked to invite the teacher to enter a conversation that shifts the dominant story of segregation. I know she still wonders if inclusion is the right choice as she works to make it successful. As time passes and supports are put into place, I find it exhilarating to watch this teacher support this student, to understand a new possibility for who she, as classroom teacher, can be for all her students.

I know support for this child's inclusion is still tenuous. Valerie and Sandi, as your stories taught me, I need to keep a watchful eye on this student's inclusion. Your narratives taught me this child's inclusion is not about this year but about twelve years and beyond. The inclusion of this student is not only for this student but also for other students. This student's inclusion is a chance to change the dominant social narrative of segregation for her and other students. This student's inclusion will need tending and attention. I must respond with care to both the family and the teaching staff to ensure this student and future students' success. Changing a dominant social narrative is difficult. Restorying is a challenge.

In response to questions of doubt about the presence and success of this student at our school, your narratives help me to tell stories that construct inclusion as a possibility for children. My obligation, as Lopez notes, is to give your stories to others to work against the negative plotlines in which children with developmental disabilities have been cast. You did this Valerie when you presented your story to a class of pre-service teachers. Your story forced the student teachers to consider what they knew and helped them reflect on their socially constructed belief that children with disabilities belong in segregated classes. Many teacher colleagues are, as were these pre-service student teachers, caught in the plotline of special education as currently structured. Your story helped these student teachers gain a narrative understanding of your and Jason's lived experiences and created new possibilities for the children and youth these teachers may encounter in their teaching careers. My obligation is to help the teachers at our school to see new possibilities for this student through your stories.

There will be a need for a story of transition to be constructed as this student moves to the next grade. Your stories of transition alerted me to this. I am mindful of the comments of teacher colleagues as they explore their feelings of what inclusion is all about as this student moves from grade to grade. I attend to the questions of doubt and respond whenever there is a need. Signs of questioning are there. I do not avoid them. I have done this by working with the classroom teacher to figure out such things as seeking a positive way to ensure the student with the disability is able to attend fieldtrips alongside her classmates. As well I responded in an open way to the teacher's questioning if this little girl would be best served in a specialized program. The teachers' concerns resonant with concerns you encountered in your stories. As both of you have done, I tell stories in response to these questions to advocate for why this student is best served in her neighbourhood school.

Valerie and Sandi, your narratives highlighted the barriers families face year-to-year, school-to-school in securing and maintaining an inclusive education making me aware of how fragile inclusion is for children with developmental disabilities. Who the principal is and her story to live by are important in the success of inclusion. This student is in Grade 1. As your stories illustrate there will be many obstacles along the way for this child and her family. Always present on the horizon is the dominant social narrative of segregated education. I worry. Both of you had skills and knowledge of inclusion. You had a strong network of friends to support you as you encountered the challenges educators presented when they continually suggested you segregate your sons. This parent lives in a low income community and her child attends an inner-city school. I am aware of the rhetoric of equality and the reality of domination that occurs within the process of institutional policies and practices that this family will face in the next twelve years. This child's inclusion is not safe. This child's family's social and economic arrangements create a greater disproportionate distribution of power and resources (Fine, 1987). I need to be thoughtful about who I am as principal, being sensitive to barriers and needing to create space for this mother to work through the barriers she may encounter as her child progresses through her school years.

Inclusion and Choice

I know I am not surrounded with people who support my views. I face conflicting stories when my own narratives for the education of children with developmental disabilities do not coincide with teachers' and principals' taken for granted stories of segregation. One day, I sat at a principal meeting and participated in a brainstorming session on how we support the diverse learning of students at our school. I shared the pride I had in my teacher colleagues' abilities. I told a story of how the teachers questioned the hiring of a teacher for our school who talked about the need to separate and segregate children who were having difficulty from those who were more capable as a strategy to deal with diverse groups of learners. My teacher colleagues had said that a teacher who viewed this as an effective approach would not be a good match for our school and rejected him as a candidate for the position. They said we included students with disabilities at our school because all students needed to feel accepted if they were going to be successful.

I shared this story to represent how my colleagues worked to accommodate the diverse group of students that attended our school. The teachers' knowing that there are possibilities for another plotline for children with developmental disabilities, I believe, strengthened my colleagues' skills as teachers. My fellow principals welcomed the story as a fine example and it was recorded on the chart. As I got up to use the washroom, I heard the conversation shift to the importance of segregation, as well as inclusion, as an option. Upon returning to the room, one of my colleagues pointed out, the group felt it was necessary to note the range of program options for students with disabilities and that we must record segregation as a valued choice. This had been recorded beside my comments on the skills I had seen the teachers having because of the degree of inclusion at our school. My colleague informed me, knowing my conviction for inclusion, there was agreement to point out this addition upon my return to the room. I was not surprised by this outcome. Having advocated for inclusive education for over fifteen years it was a common retort to my suggestion that inclusion was instrumental in many ways. Valerie and Sandi, I have come to understand the competing political goals (Riddell, 2000) this discourse presents. Your narratives illustrate how the notion of inclusion presented as a choice, rather than as a governing principle, keeps segregation, the dominant narrative, present on the horizon as a direction for your sons. At this meeting, I was reminded of how often the bias towards the dominant social narrative of segregation is at the heart of the question, is inclusion right for this student with a developmental disability?

Glimmers of Possibilities

Valerie and Sandi your narratives of the strides your children made as students in inclusive schools gave me hope that there would be signs to support having this young girl attend her neighbourhood school. Just recently the signs of a new story began to arrive. Her mother, who is very quiet and reserved, arrived one day in the school office. She wished to tell me she appreciated all the supports this school gave to her children. She arrived quietly and left just as quietly after sharing her appreciation. This was an overwhelming gift for me, a rare gift from our parent community. It is a gift I shared with the school staff.

Another glimmer of hope for change arrived when I attended a function over the Christmas holidays. At the event, I was seated at a table with a long time volunteer from my school. This volunteer is a mentor to one of the siblings of the student with a developmental disability. The mentor told a story that gave evidence of the power of attending your neighbourhood school alongside your brothers and sisters. He shared one day he was sitting reading with his mentee in the school library and her sister with the developmental disability came into the library. The younger sibling saw her sister, came up to her and crawled into her lap. The older sibling hugged her sister and went on reading without missing a beat. The mentor expressed how impressed he was with the power of these children's relationship and the love the older sibling had shown for her younger sibling.

Sandi and Valerie, as you do, I took this opportunity to alert this gentleman to the possibility of another social narrative for children with developmental disabilities. I shared how the parent's request to include her daughter could have been refused and I challenged him to think about what that would have done to this strong family bond he witnessed that day. I reinforced how, as principal, I had the power to make or break such a bond and how my support of this young girl attending her neighbourhood school had strengthened the bond between these two sisters.

TWELVE YEARS LATER

Miracle on 34th Street

My life is immersed in relationships with families whose children have a disability and who are included in their neighbourhood schools. I believe this is because of my passion for the social justice of inclusive education. On December 16, 2001, I was shown the miracle of parents like you, Sandi and Valerie, who choose inclusion for your children in light of the opposition you face almost daily. As friends of the Eggert family, my husband and I were invited to see a play their daughter Margaret was in. She was a member of the choir and they were performing at the local town centre. Our friendship began 12 years ago when my husband and I helped the family secure an inclusive education placement for their daughter. This family's case is what Alberta Education referred to as a "landmark special education placement decision" in which the minister directed a board to include a child in her neighbourhood school (Alberta Education 1990).

Margaret has been included in her neighbourhood school for the past 12 years and is close to finishing Grade 12. Her inclusion has not always been easy. Although the Minister of Education directed the school board to provide a fully supported inclusive education Margaret's parents encountered educators who lived the dominant social narrative of segregation and did not support inclusive education. I know this as I attended, during my years as a graduate student, a number of IPP meetings with the family to help support both the parents and teachers. I witnessed a meeting where a teacher told the family there are drawers for students and each student has a drawer in which she belongs. The drawer they were asking for, for their daughter (inclusion), was the wrong drawer. She fit best in the segregated drawer. This was a painful experience for the family as have been many of the meetings both of you attended when professionals wished to limit your children's potential. The Eggerts, like you, stood their ground, thanked the teacher for her opinion but reiterated they saw inclusion as the right choice for their daughter. On December 16, 2001 the choice of 'the drawer of inclusion' was confirmed as being right for Margaret.

On that day, I sat in an audience of over 250 people watching the play *Miracle on 34th Street*. Margaret entered, in a short scene as part of the Santa Claus parade, centre stage. All eyes were on her as she held baby Jesus in her arms and her peers danced around her singing *Joy to The World.* That evening I observed something that was not apparent to anyone in the audience that did not know Margaret. Margaret is a young woman with a significant developmental disability. I was moved by Margaret's performance, the valued role she held and the skill of her drama teacher that believed.

An article, in the Edmonton Journal on December 22, 2001, titled "Margaret Eggert: 12 years later making the most of her potential," featured Margaret's accomplishments and participation in the play "*The Miracle on 34th Street.*" The article captured what I saw, "When you see her on stage she is just one of the other kids. ... That would not be the case if her parents had listened to the school board and allowed her to go to a segregated program" (p. B2). I noted many miracles that evening: the miracle of Margaret's teacher who found a way to include her in all aspects of the high school music and drama program; the miracle of Margaret's parents who resisted continual pressure to segregate their daughter; and the miracle of Margaret, a young woman, who is just one of the kids.

Fragility of Inclusion

The dominant narrative of segregation remains a competing story with inclusion. Inclusion of children with developmental disabilities in the regular classroom is fragile as seen by the present Minister of Learning's comments reported in the Edmonton Journal

January 3, 2002. "Educating special-needs students in regular classrooms may be too hard on teachers, says Learning Minister Lyle Oberg" (p. A1). Oberg went on to say as reported by the journalist, "Teachers who have these kids in their classrooms are going beyond the call of duty in what they do" (p. A1). The dominant social narrative of segregation once again attempts to story students with developmental disabilities as other and that they would be best educated away from their peers without disabilities. The minister's comments came just before a pending provincial teachers' strike in which teachers were asking for a raise in salary and decreased class size so as to effectively meet the growing demands of the students in the regular classroom. The Minister of Learning blamed Margaret and your children, Valerie and Sandi and all the other parents who request inclusive education for the undue stress teachers are experiencing. He sees your children as the reason for teachers' negotiation demands.

Dr. Oberg's comments in the article "Special-needs students stretch teaching resources" have reinforced the fears of parents who seek inclusive education for their children. Although this government has spoken for the support of inclusion since the early 1990s inclusion of children with disabilities in education has remained patchy, insecure and emerges unsupported by policy frameworks of this government. The dominant narrative of segregated education remains prominent as to what is best for students with developmental disabilities. What seems to continue to happen to children with 'special needs' is that they tend to be viewed as a marginal issue, which is expendable in a crisis, such as the up coming teachers' strike.

Valerie and Sandi, in times of transition in your sons' inclusion, your stories illustrate this notion of marginalization and expendability. Dr. Oberg's comments are part of the public gaze both of you experienced in securing and maintaining inclusive education for your sons. As parents, you have had to seek the supports your children need even when those in authority and those who have the power to influence the conditions for the right resources to be made available for both your children and their teachers so openly reject your children's right to be present in the regular classroom.

Where to Now?

Where will inclusion take me? As Connelly and Clandinin (1999) said "(w)e are just in the parade hurrying along and no one has said where it ends and no one knows the route that it is taking" (p. 122). It is the "where to" that is puzzling. Where will my commitment to inclusive education take me? I have been in the parade for over fifteen years. The parade has had no path, the parade has no route, and the parade has no end. But I am in the parade for the duration Sandi and Valerie. Your narratives will shape where I go in the parade.

Thank you for your stories. I hold them dearly in my heart.

Gratitude is the heart's memory. (French Proverb)

With Warm Regard,

Heather

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Research Consent Phase One

Researcher: Heather Raymond, PhD. Student, Department of Elementary Education, University of Alberta

Telephone: 780-451-3246; **Fax:** 780-492-0113; **Email:** hraymond@epsb.net

Supervisor: Dr. D. Jean Clandinin, Centre for Research For Teacher Education and Development, University of Alberta, 780-492-7770 Ext. 290

Title Of Study: Parents as Advocates: Securing Inclusive Education for Children with Developmental Disabilities

You have been asked to participate in a research study. The purpose of the study, terms of your participation, as well as any expected risks and benefits, must be fully explained to you before you sign the attached form and give your consent to participate.

You should also know that participation in this research is entirely voluntary. You may refuse to participate, or may withdraw from participation at any time during the study without jeopardy.

Purpose Of Research: Little research explores parental experiences with advocating for inclusive education. In the proposed research I seek to gain an understanding of, and to make meaning of, parents' narrative advocacy experiences in securing inclusive education for their children with developmental disabilities. My inquiry intention is to hear the stories of parents' expereinces of gaining inclusive education for their children. Through hearing their stories, narrative inquiry will allow me to create a research text that will illuminate the experiences of parents.

Methodology: The proposed research will use narrative inquiry. In the first phase of the proposed reasearch I wish to explore the stories of two parents' advocacy efforts to secure inclusive education for their children with developmental disabilities. You are being asked to partcipate in a series of extensive conversations. The number of meetings will be determined and negotiated between us as we work together. I anticipate there will be a maximum of five interviews of no more than 1 and 1/2 hours each time. These conversations will be tape recorded.

In the second phase of this research I will invite five parents, whose children are included in their neighbourhood schools, to participate in two group conversations. In one of the conversations your story will be shared prior to the group coming together. This group of parents will be asked to reflect upon your narrative account and to make meaning of this account in relation to their past, present and possible future advocacy efforts for their children. These conversations will be tape recorded.

Anonymity Or Named In The Study: If you choose anonymity you will be guaranteed that your responses will be treated with confidentiality and a pseudonym will be used in the writing-up of the study. Your right to anonymity is paramount, and information that you feel could subvert your anonymity will not be included in the study.

OR

You may choose to use your first name in the write-up of the study. However selecting this option and signing your name indicates that you understand the risks of using your own name.

If at any time you have questions regarding this research or your participation in it, you should contact me at 780-451-3246 to ask your questions.

Sincerely,

Heather Raymond

CONSENT FORM PHASE ONE

NAME ______________________________

ADDRESS ______________________________

CITY ______________________________

POSTAL CODE ______________________________

TELEPHONE ______________________________

EMAIL ______________________________

I agree to participate in phase one of the study. I understand that I will participate in a series of tape-recorded interviews and my story will be shared with parents in phase two.

OR

I do not agree to participate in the study.

____

I wish to remain anonymous in the research.

OR

I wish to use my first name in the research. I understand the risks involved in using my first name.

____

I give my permission for the research to be used beyond the dissertation work in presentations and in other forms such as academic journals.

OR

I do not give my permission for the research to be used beyond the dissertation.

Date: ____________________ Signature: ______________________________

Research Consent Phase Two

Researcher: Heather Raymond, PhD. Student, Department of Elementary Education,
University of Alberta

Telephone: 780-451-3246; **Fax:** 780-492-0113; **Email:** hraymond@epsb.net

Supervisor: Dr. D. Jean Clandinin, Centre for Research For Teacher Education and
Development University of Alberta, 780-492-7770

Title Of Study: Parents as Advocates: Securing Inclusive Education for Children with
Developmental Disabilities

You have been asked to participate in a research study. The purpose of the study, terms of your participation, as well as any expected risks and benefits, must be fully explained to you before you sign the attached form and give your consent to participate.

You should also know that participation in this research is entirely voluntary. You may refuse to participate, or may withdraw from participation at any time during the study without jeopardy.

Purpose Of Research: Little research explores parental experiences with advocating for inclusive education. In the proposed research I seek to gain an understanding of, and to make meaning of, parents' narrative advocacy experiences in securing inclusive education for their children with developmental disabilities. My inquiry intention is to hear the stories of parents' experiences of gaining inclusive education for their children. Through hearing their stories, narrative inquiry will allow me to create a research text that will illuminate the experiences of parents.

Methodology: The proposed research will use narrative inquiry. In the first phase of the I explored the stories of two parents' advocacy efforts to secure inclusive education for their children with developmental disabilities.

You have been invited with three other parents, whose children are included in their neighbourhood schools, to participate in two group conversations. Prior to the group coming together you will be asked to read the parents' narratives, which were collected in phase one. In the group conversation you will be asked to reflect upon these narrative accounts and make meaning of this account in relation to your past, present and possible future advocacy efforts for your children. These conversations will be tape recorded.

Anonymity Or Named In The Study: If you choose anonymity you will be guaranteed that your responses will be treated with confidentiality and a pseudonym will be used in the writing-up of the study. Your right to anonymity is paramount, and information that you feel could subvert your anonymity will not be included in the study.

OR
You may choose to use your first name in the write-up of the study. However selecting this option and signing your name indicates that you understand the risks of using your own name.

If at any time you have questions regarding this research or your participation in it, you should contact me at 780-451-3246 to ask your questions.

Sincerely,

Heather Raymond

CONSENT FORM PHASE TWO

NAME ______________________________

ADDRESS ______________________________

CITY ______________________________

POSTAL CODE ______________________________

TELEPHONE ______________________________

EMAIL ______________________________

I agree to participate in phase two of the study. I understand that I will participate in two group conversations, which will be taped-recorded.

OR

I do not agree to participate in the study.

____

I wish to remain anonymous in the research.

OR

I wish to use my first name in the research. I understand the risks involved in using my first name.

____

I give my permission for the research to be used beyond the dissertation work in presentations and other forms such as academic journals.

OR

I do not give my permission for the research to be used beyond the dissertation.

Date: ______________________ Signature: ______________________________